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Loitering in a liminal space: Enactments of differing realities of hallucinations in dementia

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Declaration

I hereby declare that this thesis:

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Barbara Elizabeth Taylor

Abstract

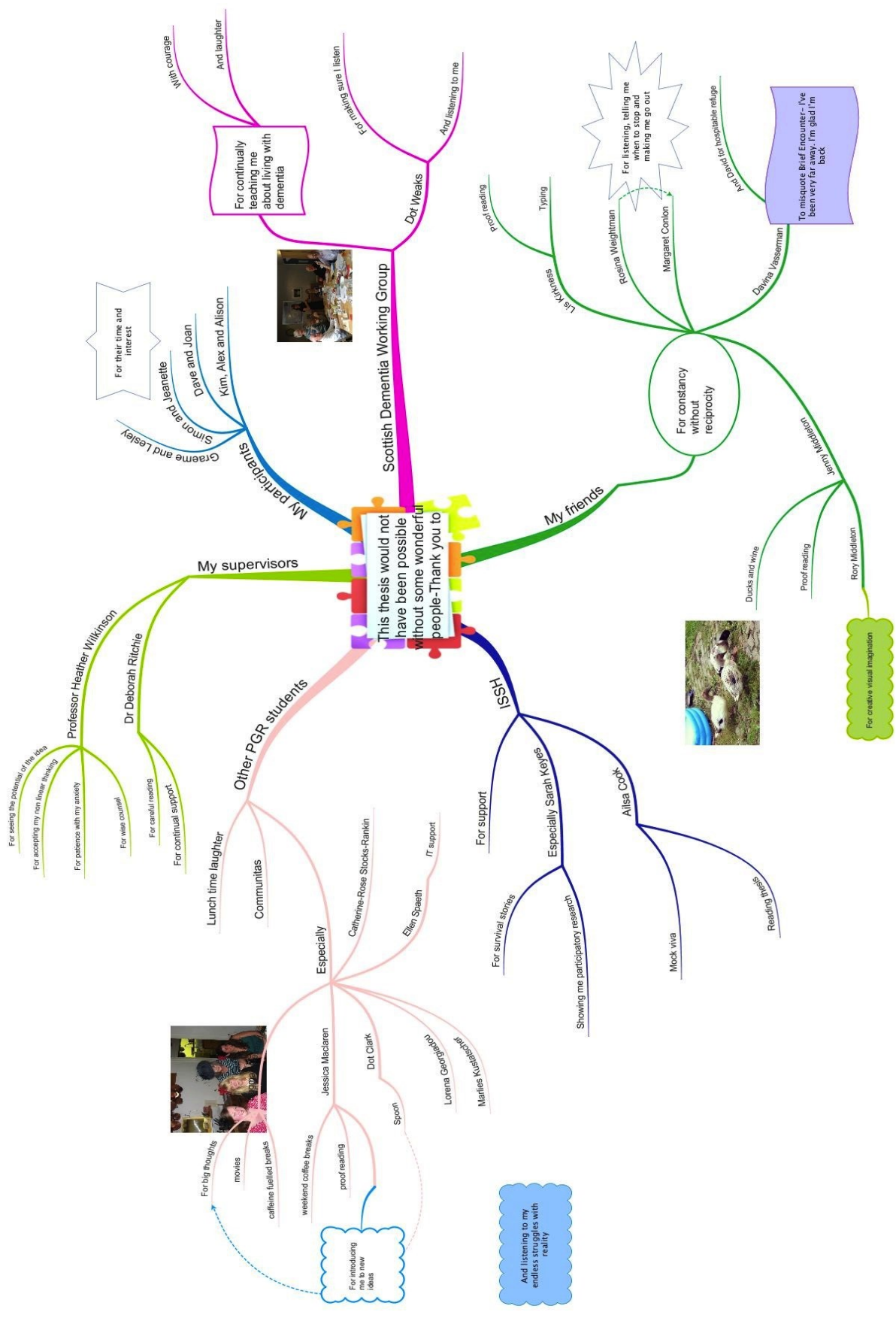
This thesis uses a narrative approach to explore how hallucinations are understood by people with dementia, their carers and community mental health nurses. The study aims to make visible the multiple enactments of realities of hallucinations as they are practiced within a community mental health setting. While existing research shows a growing body of research about experiences of dementia, the experience of hallucinations has been unexplored. Research about hallucinations has predominantly focused on epidemiology or pharmaceutical interventions.

The research was conducted in one area of Scotland, using three triadic case studies comprising a person with dementia living at home, their carer and community nurse. Data were collected through conversational interviews. In this study realities are conceptualised as enacted and multiple. The study was informed by an ethic of care approach which critiques the view of people as isolated individuals. People are understood to live in relationships within which they co-construct narratives. It provided an ethical framework to research relationships and data analysis. Data were analysed using voice centred relational analysis, which uses four separate 'listens' for each interview. This method identifies the multiple voices speaking and allows a high degree of reflexivity. I-poems were produced for each of the interviews and some visual illustrations were used in different ways to illustrate the analysis and allow an alternative interpretive perspective on the data.

The analysis reveals that people with dementia and their carers contextualise their understanding of hallucinations into their narrative identity. They strive for continuity but also experience them as potential threats. Ambiguity and uncertainty are characteristic of the experience of hallucinations of people with dementia and carers and I suggest that liminality is a useful concept to understand this. Community nurses have multiple, and fluid understandings of hallucinations; they negotiate these different hallucinations within a situated practice enactment. Their

decision to act on hallucinations does not depend on whether they relate to consensus reality, but whether they cause distress.

The findings of this study highlight the complexities and ambiguities of hallucinations within dementia and shows how they are managed in practice. The theoretical perspectives of enacted realities and ethic of care, alongside creative methods enhances understanding of the ephemeral nature of hallucinations. This study adds to literature challenging the exclusion of the people with dementia from research by demonstrating that they are able to talk about their experiences of hallucinations. The study contributes to the story of hallucinations in dementia by disrupting the fixed boundaries of the dominant discourse that views hallucinations as a clear cut break with reality.



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1 Introduction

This thesis and the research on which it was based concern narratives of hallucinations in dementia. The aim of the study was to explore differing realities of hallucinations of people with dementia, their carers and community mental health professionals. The research questions were

- How do hallucinations affect the daily lives of people with dementia?
- Do hallucinations impact on the self-identity of people with dementia?
- How do the multiple practices of dementia and hallucinations hang together?

I examined how people with dementia living in their own home, and carers, made meaning from hallucinations in dementia. This allowed for an examination of how a person, and a carer, each impact on the identity of the other, acknowledging that people do not live in isolation from each other. The experiences of the people with dementia were set alongside those of their carers and the mental health professional who visited them.

In this brief introduction I set the background and context for this research, including two clinical stories from my past that provide examples of the impetus for the study. I acknowledge some of the difficulties that arise in studying something as ephemeral as hallucinations. Finally I present an overview of the chapters that comprise the main body of the thesis.

1.1 Context for the study

1.1.1 Hallucinations

The definition of hallucinations used here is predominantly a psychiatric one - perceptions experienced by someone, which other people do not perceive. The dominant understanding of hallucinations in the western world comes from psychiatry. Historically they have been understood in different ways (Al-Issa, 1995, Lukoff, 2007) and the psychiatric understanding continues to be contested in the present day (Henderson and Henderson, 2002, Hornstein, 2012).

Within western psychiatry, hallucinations are a symptom, often of psychosis but also of a variety of organic illnesses, including dementias (Sacks, 2012). Dementia is a syndrome comprising a number of diseases (Jacques and Jackson, 2000, Brown and Hillam, 2004). I argue that the implied singularity of the disease model is too simplistic, hallucinations in dementia are not only multiple, but also shape shifting. They are elusive, they change, and boundaries are crossed and troubled in ways that are difficult to pin down. Categories make absences (Law, 2004), in this case they make absent the social context and uncertainty inherent in hallucinations.

This thesis attends to the ways that people experience and understand hallucinations, and integrate them into narrative identities. By focusing on the experiences of people with dementia, it draws on, and contributes to, the growing body of research seeking to engage with the subjective experience of people themselves (Wilkinson, 2002). In the majority of previous research studies, hallucinations in dementia have been decontextualized; they have been understood as a psychiatric symptom of a biochemical disease of the brain. This definition ignores the more complex interpersonal, clinical and political meanings of both hallucinations and dementia.

1.1.2 Dementia

Dementia currently has a high profile on the political agenda in the UK, with each individual country producing their own dementia strategy. The strategies argue that they were created as a response to both a demographic crisis, and to improve the individual journeys of people with dementia.

Within the UK at the present time, both dementia and hallucinations are mainly diagnosed by older people's mental health services. Community mental health professionals are, therefore, likely to come into contact with people who hallucinate. In modern Western society, hallucinations are traditionally sited within a psychiatric frame of reference. Since 1906, with the discovery of the neurological changes that went on to constitute Alzheimer's disease, the dominant paradigm of dementia has been medical (Cheston and Bender, 1999, Maurer et al., 1997).

A diagnosis places signs and symptoms within an explanatory framework that is value-laden (Bracken and Thomas, 2005, Hughes, 2011). The implications for a person receiving a psychiatric diagnosis, including a diagnosis of dementia, have been well documented (Kitwood, 1997, Harding and Palfrey, 1997, Hughes et al., 2006, Sabat, 2001, Sabat et al., 2011, Bracken and Thomas, 2005, Busfield, 2000). Both dementia and hallucinations are feared because they attack our concepts of what it is to be constituted a person, resulting in assumptions of loss of selfhood (Kontos, 2006, Ballenger, 2006).

There has been a dearth of literature about hallucination and dementia. Studies have been anecdotal and reliant on reports of other people, such as caregivers, both family and paid (Berrios, 1992, Gustafson and Risberg, 1992, Cohen-Mansfield and Golander, 2012). One recent qualitative study examining the experience of people with dementia and visual impairment identified that some people experience hallucinations as a compounding feature in visual impairment, and that caregivers were unsure how to manage them (Lawrence et al., 2009). There are a limited but growing number of studies of the subjective experience of people with schizophrenia, who hallucinate, but they too remain rare within academic literature (Thornhill et al., 2004, Karlsson, 2009).

1.2 But what is reality?

The question of reality has plagued or perhaps preoccupied me throughout this research. This whole project may be seen to concern reality, and like most other people I am certain that I know what that is. There is little dispute that people generally conduct their everyday lives under the assumption that there is a real world out there, that is experienced by everyone in very similar ways, and can be known to a greater or lesser extent (Law, 2004, Gillett, 2004, Radley and Chamberlain, 2001). Hallucinations and delusions presuppose a definite objective view of reality against which they can be measured (Pollner, 1975). A common-sense view of reality would lead to the conclusion that hallucinations are not real, although my experience when talking to some people with hallucinations is that they can suddenly change, and there are times when I am not sure how or when this happens, so reality shifts.

1.3 Writing uncertainty

All texts...are edited, selected, pruned and spruced in order to draw the eyes of the reader towards certain spaces.

(Speedy, 2005: 63)

It has become a truism to say that the way research is reported does not reflect the reality of the process. Academic writing has been linear, ordered and detached. The author disappears, leading to the semblance of an authoritative, 'objective', single truth (Fleischman, 1998). Interviews are selective and focused; the researcher then concentrates the material even more, to tell their own story of the interviews.

In a world where there is a multiplicity of nuanced and sometimes contradictory narratives, it becomes a challenge not only to capture them, but also to know how to express them to a reader (Smart, 2009). How am I to turn the mess, that is the world (Law, 2004), into some sort of order, without descending into total fragmentation, so that my thinking is comprehensible, without actually losing a sense of the mess?

The topic of my study is hallucinations and dementia, how can I 'know' what is going to be a different reality to mine, and that of most other people with whom I assume I share a common reality, and how should I best describe it? Making a text out of hallucinations requires the experience to change from an internal perceptual one to an external linguistic representation. It addresses the limits of the verbal, and requires decisions about how to find words to express a non-verbal experience. I have chosen to use poetic, and some visual, representations to try to convey other positions.

Although I used a narrative methodology within this study, a narrative does not represent reality but only how we chose to create it (Mischenko, 2005) Narrative form is ordered, the world is disordered, the world of dementia and 'madness' is disordered even more so, it may be impossible to write a structured narrative. Creating structure into this narrative changes the nature of the experience. Creating an unstructured narrative, however, risks further banishing people with dementia as problems, and less than full members of society.

1.4 Background

I do not believe that I can bracket out my experience. As Mauthner and Doucet point out the reason we follow up certain ideas is influenced by ‘our own personal, political and theoretical biographies’ (Mauthner and Doucet, 1998: 122). It was my experience as a clinical practitioner that informed my choice of subject. The way I relate to people with dementia and carers has led to methodological decisions, and the practicalities of how I relate to people during the research. I have worked as a community mental health nurse for many years and am therefore interested in how other community mental health practitioners view hallucinations. This also means that I share their training and similar experience.

This thesis needs to be understood first and foremost as situated, situated within my experience, my pre-occupation and my ‘fascination’ as Jennifer Mason (2011) so cogently describes. My fascination is with hallucinations. I make a choice as to which story of hallucinations and dementia I use to begin this thesis, there have been many throughout my career, but some are more memorable than others. There are also many stories that can be told about each encounter. Two stories in particular from my practice illustrate my fascination with hallucinations.

This project begins then with John, a man with a diagnosis of Lewy body dementia. He lived with his physically disabled wife, and in many ways was her carer. They had a reciprocal caring relationship. John had mild memory problems and knew me as a community nurse whose visits involved discussions with both himself and his wife. One day he opened the door for me and said he would find his mother, he went upstairs shouting for his mother. He was obviously distressed by being unable to find her, saying she had been there a few minutes ago. I had assumed that he meant his wife but he had rushed past her. She was sitting in the living room and her obvious presence did not seem to satisfy him. I cannot recall how this situation ended but I know it calmed down quickly. It preoccupied me though, and I wanted a model of some sort to make sense of it. My analytically trained supervisor suggested attachment theory, which gave me an explanation, and satisfied me for some time. Attachment theory was developed by Bowlby (1971) to theorize the way that infants

develop strong relationships, and the anxiety that ensues, with the separation from the attachment figure. More recently there has been an interest in explaining the behaviour of seeking important figures throughout life, including in dementia, as a response to anxiety provoking situation (Miesen, 1993, Stanley, 1993, Doucet and Mauthner, 2002).

The problem with this theory is that it may explain the cause of the behaviour in this instance, but I have known other people with dementia where this does not seem to be the case. Some years later another memorable encounter disturbed me even more, because I felt I did not know how to resolve it.

Alex lived alone, having moved from a different town to be closer to his daughter. His speech was often confused, disadvantaging him in conversation (Shakespeare, 1998). His social manner remained polite and I took advantage of both these features to gain access to his house. I justified my actions to myself as a necessary response to the assumed risks of him remaining at home, expressed by his doctor and family. On one visit he was extremely distressed, talking about fires and then people being in his house. I knew he thought people from the television came into the house and also that he thought his reflection in the mirror was an intruder but on this occasion he rushed into the bedroom and pulled suits out of the wardrobe. I did not understand whether he thought they were people, or where he thought the fire was, and tried my usual repertoire of responses to calm him down. Telling him I did not see what he saw but believed him did not help. Finally at a loss, I told him I did not know how to help, but that I thought he would be safe. He visibly relaxed and said he believed me. Although I was relieved that something had finally worked, I wondered how long this would last, given that I was going to leave him alone. It left me questioning what the best way of responding to these situations is.

The impetus for this study was twofold, an aspiration to understand what was happening, a naiveté on my part at this early stage that I would find **the** answer, and a desire to improve practice.

1.5 The search for certainty

My move to an academic situation was driven by a desire to solve practice problems. I initially struggled to find 'the answer' and found it difficult to relinquish a need for certainty and security in my search for understanding. I moved from a solid belief in my practice knowledge, to a search for what I now see was universal, context-independent knowledge. As Law et al argue

the will to purity is powerful: but it is none the less a chimera

(Law et al., 2013: p11)

For a time I forgot what I knew, in my desire to achieve that idealised, impartial knowledge.

As Back (2007) has pointed out, the claim to know whole truths has led to many of the atrocities of the twentieth century. Political science is full of examples where closure is not achieved by force or logic (Mol, 2002). My first degree is in political science, I should know better. The research process involves both theory and practice (Ribbens and Edwards, 1998), and this study needed to integrate my knowledge from working as a mental health nurse, with theoretical understandings, and the practicalities of research.

There are different ways of knowing, and different stories can be told; I am aware of, and even comfortable, with this in practice, although have often been in the position where other people have wanted a definitive answer from me that I was unable to give. Law (2006) argues that it is easier to achieve coherence in theory than in practice.

The study originated from my own experiences as a mental health nurse. My understanding of dementia is contextualized by my experience as a nurse, educated within a model of psychiatry, but also by my earlier education within the radical politics of the nineteen seventies. I assume that people with dementia are able to speak about their own experiences, that they live within relationships and in a society, which impinges on their experiences.

1.6 Organisation of the thesis

Chapter 2 presents a selected review of the literature. As stated earlier there have been few studies on the subjective experience of hallucinations in dementia. I conducted a narrative review of the main themes in the field of dementia relevant to my research questions. This review focuses on the multiplicities of discourses of dementia and hallucinations. The study is set within a medical context and so the different understandings within disease and illness are discussed. The diverse approaches to the self and identity impact on the way people are treated by society and by other individuals. I include a personal story that illustrates the conflicts that can arise between ideas of the self and the relationality of care. I demonstrate that the unity of medicine that can be assumed in the discourse of disease, and diagnosis, is not accurate and that we need to address the realities enacted in practice.

Chapter 3 develops this discussion by examining some of the theoretical understandings of multiplicity and situated knowledge. The work of John Law and Annemarie Mol were especially useful in developing my understanding of boundaries and elusiveness. Finally I discuss an ethic of care framework, which provides an underpinning for my research approach. This offers an ethical understanding of people within relationships that continues to challenge the view of the isolated individual, inherent in the discussion of the loss of self in the previous chapter.

Chapter 4 describes the design and the conduct of the research. Some of the dilemmas I faced as a researcher researching my own community are examined alongside challenges to my sense of myself as a novice researcher.

Chapters 5, 6 and 7 present the data from my study. Each chapter is a separate triadic case study prefaced by an illustration. They are presented as separate realities of each of the participants, person with dementia, carer and nurse.

Chapter 8 draws together the findings from the data into an exploration of narrative understandings of hallucinations. Understandings are contextualised, and dementia may be a part of the context, inseparable from the narrative of hallucinations.

Chapter 9 uses liminality as a theoretical framework to understand hallucinations in dementia.

Chapter 10, the final chapter, reflects on the implications of the study for practice and future research and offers a final reflection of the research experience.

2 Competing discourses

This study aims to explore different realities of hallucinations experienced by people with dementia, their carers and community mental health professionals. It is located within a community mental health site of practice, where there is increasing dialogue between medical discourse and the experiences of those with the illness (Bracken and Thomas 2005). The research questions address the impact of hallucinations on the identity of the person with dementia. Within dementia studies there has been an important debate about the self and dementia that has implications for understanding identity. This chapter locates the background to the study in the bodies of literature from which it draws and hopes to influence. It is located within differing theoretical understandings of dementia. It can be argued that dementia is an organic medical disease as evidenced by changes in the neurological structure of the brain. The growth and implications of dementia as a medical disease is considered first. This is followed by a number of challenges to the medical agenda that focus on the ways people are living with dementia and other chronic illness. The assumption that medicine is singular is disputed, as illustrated in the section on the agenda of evidence in health research. I end with a personal reflection on an incident with my mother that challenged some of my own rhetoric of care.

2.1 Introduction

There are opposing discourses of dementia with differing emphases, which can lead to ambivalence and contested territories (Clarke et al., 2010: 695). I want to bring my practical clinical experience and being a daughter together with my selected literature to inform my study. I am interested in multiplicity, the multiplicity which somehow hangs together in hallucinations and dementia. There is an assumption that when we talk about a disease or a symptom this is a singular reality but in practice there may be many realities, this is considered in more detail in the following chapter. I review some of the multiple conceptualisations of dementia that are relevant to the practice of care. These are dementia as a disease, illness narratives, personhood and socio-political discourses. Care is complex and is not informed by a

single understanding of disease. Tensions can be experienced and managed in different ways within the same healthcare setting (Moreira, 2010).

Although I use the terms dementia and hallucinations, this does not mean that I am accepting them uncritically. The etymological root for 'dementia' is *demens* meaning out of your mind. Calling someone 'demented' is now considered an insult, and 'dementia' may well be associated with these synonyms. Within a medical definition, dementia is an umbrella term rather than a single disease, but groups such as the national Alzheimer Societies (Alzheimer Scotland Action on Dementia, 2013, Alzheimer Society, 2013) have chosen not to use 'dementia' despite working with people with any type of dementia. The founding of Alzheimer's societies is closely linked to the re-creation of Alzheimer's disease as a disease as discussed in the following section. I will use the term dementia throughout this thesis in line with the Scottish Dementia Working Group (Scottish Dementia Working Group, 2013) practice, unless there is a reason to use the name of a specific disease. I also chose to use the term person with dementia as it places the person before the dementia. In this study I do not use the term carer to describe someone who is paid on a contractual basis to provide care such as a nurse or careworker in a care home. I use carer to describe a significant other who is in a relationship with the person with dementia, for example a family member or friend.

2.2 Dementia as a disease

Dementia was labelled as a disease entity for the first time in the United States in 1976. It is argued that this was due to political lobbying by carers who set up Alzheimer's societies and medical researchers. Before the 1970s Alzheimer's disease had been understood as a rare condition which affected people under 65. In 1976 it was reclassified and became one of the most common diseases in the Western world, and a major cause of death. The apparent increase in incidence was used to enhance funding and increase the status of medical research. Changing the way it was understood, had implications for individuals, whose roles changed. Doctors become experts and people with dementia become patients (Cheston and Bender, 1999, Fox, 1989, Davis, 2004).

The medical definition of dementia is established by organizations such as the World Health Organization and the American Psychiatric Association. The definitions used by both organizations are very similar and are in common usage throughout medical practice (Brown and Hiram, 2004, Jacques and Jackson, 2000). Dementia became constructed as a biomedical disease, situated within the neurological changes in the brain (Davis, 2004). There are, however, on-going debates about whether Alzheimer's disease exists as a disease or whether the neurological signs are part of the ageing process (George et al., 2011, Lock, 2011). The discourse of dementia as a disease is based on a neuroscientific understanding, with dementia placed firmly in the brain. It accounts for a consciousness without reference to the world outside.

Critiques of a medical paradigm of dementia have come from social psychologists (Kitwood, 1997), social constructionists (Harding and Palfrey, 1997) and more recently within the narratives of people with dementia themselves (Sterin, 2002, McKillop, 2002, Bryden, 2005).

Social scientists question the claims of science to neutrality, arguing rather that it is socially situated (Harding and Palfrey, 1997, Prior, 2003, Law, 2004). The classification of dementia results in pathologisation of behaviour and social skills. In common with other mental illnesses, behaviour becomes part of the disease process (Cheston and Bender, 1999). It ignores the social context and experience of people with dementia and can result in care practice and societal assumptions that places people with dementia as problems awaiting a medical cure.

2.3 Hallucinations in dementia

Western medicine understands hallucinations as symptoms of disease, often of severe illness. They are one of the principal diagnostic criteria for schizophrenia, but can also be found in other disease processes such as dementia and delirium. Modern understandings that hallucinations are pathological are a recent phenomenon.

Esquirol, the early French psychiatrist, first associated hallucinations with madness in the 1830s. Until that time they were associated with the supernatural, rather than located in the brain (Sacks, 2012). In the Middle Ages, visions, voices and dreams were all named as visions, and were usually integrated into religious experiences

(Kroll and Bachrach, 1982). Hallucinations are a universal experience, which are attributed differently in different cultures and different historical periods (Kroll and Bachrach, 1982, Al-Issa, 1995). They can occur out-with psychiatric diagnosis, associated with sleep deprivation, bereavement and sensory isolation (Sacks, 2012, Al-Issa, 1995, Hornstein, 2012). When they enter diagnostic terminology they become pathological.

Henderson and Henderson (2002) explore how the hallucinations of an American Indian woman were attributed to her 'speaking to the other side'. Medical descriptions of hallucinations, delusions and misinterpretations exist out-with social context although it is recognised that stressful experiences such as bereavement can often result in hallucinatory experiences. A social constructionist context addresses the discourses that society uses to understand concepts and within which individuals shape experiences (O'Connor et al., 2007, Burr, 2003). A social constructionist view questions the way that pathology is judged. Behaviour is seen as part of a disorder that is socially, rather than biologically determined, leading to the problematizing of the individual who does not conform to the shared view of reality (Palmer, 2000).

The hallucinations that are symptomatic of schizophrenia are predominantly auditory, but those in dementia and delirium are often visual (Larøi et al., 2012). Visual hallucinations are defined within the DSM (Diagnostic and Statistical Manual) (American Psychiatric Association, 2013) as 'visual perceptions without adequate visual stimulus' (Mossiman et al., 2006: p154). Estimates of the prevalence of hallucinations and delusions in dementia vary, but it is generally agreed to be higher than would be expected amongst older people as a whole (Berrios, 1992). A review of 100 articles written between 1990 and 2001 identified a prevalence of hallucinations in Alzheimer's Disease ranging from 4% to 76% (Bassiony and Lyketsos, 2003). The authors put these variations down to the ways in which hallucinations, delusions and Alzheimer's disease were diagnosed. A more recent newsletter by the Alzheimer Society has suggested that the prevalence should be closer to 3%, and that the confusion has arisen because of misdiagnosis. (Alzheimer's Society, 2008). Together with behavioural problems, such symptoms are more

predictive of carer stress and institutionalisation than memory impairment (Leroi et al., 2003, Hinton et al., 2006)

Both dementia and hallucinations are primarily understood even by lay people through the definitions of scientific medicine. The advances in availability of neuroimaging techniques and genetic tests, alongside the development of new pharmaceutical treatments suggest this is where they should sit. Mental health is increasingly located within natural sciences rather than within social science (Busfield, 2000).

Differing understandings of concepts such as dementia and hallucinations over historical periods lead to different beliefs about causes. One of the ways in which medicine shapes a disease and makes it a reality is by naming it through diagnosis. The following section discusses some of the debates around diagnosis.

2.3.1 Medical diagnosis

Diagnosis is a fundamental component of medicine; it names and provides an explanatory structure to a disease. It is a universal way of classifying and reframing experiences within medical terms (Bracken and Thomas, 2005). Illness is organised as pathology as opposed to normality (Foucault, 1973). Psychiatry originates from the Enlightenment understanding of reason (Bracken and Thomas, 2005). The validity of psychiatric diagnoses has long been contested. They rely on a binary between normal and pathological that is not clear cut, but requires a value judgment (Hughes, 2011). Bracken and Thomas (2005) problematize the concept of diagnosis in psychiatry, and their arguments can be equally applied to dementia. They compare the functionality of diagnosis in psychiatry and medicine and make the point that as symptoms in psychiatry are experienced within the mind, to ignore the context has different implications than it does in physical medicine.

There have been suggestions that the term ‘dementia’ be removed from medical terminology due to its negative connotations in everyday language. Julian Hughes describes the term as ‘a conceptual mess’ (Hughes, 2011: 17). A diagnosis of Alzheimer’s disease has been criticised because of the unsubstantiated correlation of

a brain scan and cognitive decline (Rose, 2009), and the emphasis on cognitive change as the main diagnostic feature of dementia (Hinton et al., 2006, Hughes, 2011). Much clinical literature features behavioural concerns, rather than cognitive deterioration (Hinton et al., 2006). In Alzheimer's original case history of Auguste D (Maurer et al., 1997), her behavioural changes are equally central to his narrative as cognitive features.

‘She had a striking cluster of symptoms that included reduced comprehension and memory, as well as aphasia, disorientation, unpredictable behaviour, paranoia, auditory hallucinations and pronounced psychosocial impairment’

(Maurer et al., 1997: 1546)

The realities that are created have no context. We know little of Auguste D's social situation, in a similar argument, Georgaca (2003) highlights how the absence of a contextual framework for ‘psychotic speech’ renders it pathological. Psychotic symptoms such as delusions and hallucinations are reduced to biological causation and their content is rendered irrelevant (Lovell, 1997). Focusing on the purely cognitive aspects of dementia is in my opinion too narrow, it relies on a Cartesian split between mind and body which is too simplistic (Davis, 2004).

Hinton et al (2006) argue that DSM-IV criteria for dementia with its emphasis on cognitive features relegates behavioural changes to a ‘nosological borderland’ despite their prevalence within clinical literature. They describe the line between pathological and normal behaviour as being difficult to draw. They do however seem to find it easy to state that hallucinations are abnormal. I would dispute this definitive view of hallucinations. As Oliver Sacks (2012) describes in his recent book ‘Hallucinations’, difficulties can sometimes arise between the distinctions of boundaries between hallucinations, illusions, misperceptions and dreams.

A diagnosis does not adequately describe the experience of living with the disease (Beard and Fox, 2008). Although opinions about telling people they have a diagnosis of dementia are changing, a comparison to a disclosure of a cancer diagnosis, which is a common argument, can be misleading. As Hughes (2011) says

the implications are very different. Families can gain comfort from the diagnosis, which offers an explanation for the behaviour of their relative (Harding and Palfrey, 1997) but it can result in a failure to understand the social constituents of behaviour. A diagnosis may be helpful to both the person and their relatives but it also results in the person becoming subject to the 'medical gaze', which impacts on their identity (Naue and Kroll, 2008). A diagnosis of dementia can, however, be dependent on culturally and socially unacceptable behaviour (Harding and Palfrey, 1997). As has now been well documented, changes in behaviour are more likely to be responses to negative responses from other people and difficulties in negotiating the environment (Kitwood, 1997, Cheston and Bender, 1999, Hughes, 2011). Diagnoses create realities and bestow moral authority on them, making mental states governable (Rose, 2009).

2.3.1.1 Psychiatric classification

The DSM is the Diagnostic and Statistical Manual of Mental Disorders and is published by the American Psychiatric Association. It is described as a standardised classification tool for mental health professionals in the United States, and is also used in other countries including the UK (American Psychiatric Association, 2013). Describing this as a standardised tool suggests that diagnosis is clear cut but the DSM reflects much more than a standardised measure.

Documents are produced in a social context. Prior (2003) suggests we should examine texts in action and observe their role in forming identity. They make certain things visible. He describes the DSM as a generative document, a document that sets out rules. It is produced by a group of experts and enters into performance in everyday life. The DSM has undergone a number of changes throughout its history and scholars have critiqued the historical and social aspects of the changes (George et al., 2011). Petitions have been mounted for diagnoses to be added or taken away from the manual by advocacy groups such as those formed around Asperger's syndrome. Feminists and other groups have criticised some of the categories, suggesting that the categories reflect dominant social norms; most famously homosexuality was removed in the 1970s (Pickersgill, 2011, Marecek and Gavey, 2013).

It is revised at regular intervals with disorders being added and taken away. The fourth edition DSM-IV is currently used, although DSM-5, the latest edition, is coming out at the time of writing. It has been argued that DSM-III saw a change from a psychodynamic to a somatic explanation of psychiatry, which locates problems within the individual and ignores any contextualisation (George et al., 2011).

In conclusion the practice of diagnosis in psychiatry is not the objective value free process it may appear at first sight. Both hallucinations and dementia, which are of particular relevance to this study are criticised as diagnoses, because they depend on the creation of a binary between normal and pathological. This

expose(s) the need to make value judgments about such things as treatment and research.

(Hughes, 2011:26)

The line between disease and ‘normality’ is not clear cut, yet a diagnosis of dementia can change the way that people are seen and valued within our society (Kitwood, 1997, Hughes et al., 2006). Evaluation judgements are also involved in the debates about illness and disease that are discussed in the following sections

2.4 Illness and Disease

Disease is constructed as an ‘objective’ medical condition. Illness is the subjective experience of the person who is diagnosed with the disease. Medical sociology and disability studies have condemned the discourse of medicine for ignoring the experience of illness. They have done this from a number of different perspectives, medical sociology uses an understanding of chronic illness as social deviance, and disability studies frame the argument within social oppression (Thomas, 2007). Medical professionals have been urged to add an illness perspective to their knowledge of patients.

Social science created itself an area for study alongside biomedicine and called it illness, leaving disease to medicine, in a similar way to the way it separated gender and sex. However, with recent interest in the socio-material aspects of scientific

practices in ethnographic studies, there have been attempts to interlink illness and disease (Habers et al., 2002). The separation of illness and disease risks dichotomising biomedical and social or cultural knowledge (Mol and Berg, 1994).

As Mol (2002) says this leaves disease to medicine, there is little suggestion that social science add disease to its agenda whereas the picture she describes is more complex. The idea of the unity of medicine has been challenged on a number of fronts. Medical sociologists, having emphasised the social power of doctors, deriving from their monopoly on medical knowledge, began to explore the work of other health professionals and smaller groups of doctors uncovering many differences. Anthropologists too have unmasked the idea of the coherence of western medicine (McCrea and Markle, 1984). There are variances within medicine, not just between medicine and other sites (Moser, 2011). Bracken and Thomas (2005) argue that there are fundamental differences between the diagnosis of physical illness and that of psychiatric illness.

‘Medicine is not a coherent whole..(it) is a heterogeneous coalition of ways of handling bodies’

(Berg and Mol, 1998a: 3)

The tensions that have become inherent in medicine may take the form of conflict, or difficulties in co-ordination (Berg and Mol, 1998a). There has been a missing dialogue between medical caring, which is identified as professionalization leading to increase of social power, and the discourse in the nineteen seventies that tried to re value the hidden caring work of mothers as work. Within this tangle there have been analyses of the way the work of nurses has been associated with the work of women in an attempt to re-constitute it as a profession (Mol et al., 2010).

Medicalization asserts medical control over an area of life by assigning medical supremacy over it (Harding and Palfrey, 1997). It can take place at the levels of concepts, institutions, and the doctor-patient relationship (Conrad and Schneider, 1980). Criticisms of the medical model do not necessarily imply that individual health professionals ignore wider social issues within their practice. The increase in chronic illnesses over the past few decades has resulted in changes in relationships

between doctors and patients. Patients are often better informed about their own health and there has been a reduction in deference to medical authority (Bury, 2005). The growth of carers' advocacy groups, and more recently advocacy groups for people with dementia has contributed to people becoming better informed in dementia care. Highly technical scientific machinery is seldom a feature of care for people with chronic illness, except in crisis situations. Chronic illness is mostly a responsibility of primary care and people will have long term relationships with their general practitioner. A substantial feature of these relationships is that they are constituted by patient narratives of how they are coping with day to day life (Bury, 2001). People with dementia and mental health problems are more likely to be cared for in the community, and clinicians working in the community are more liable to work collaboratively with user groups and non-medical groups (Bracken and Thomas, 2005).

Bury (1982) cautions that a division between illness and disease can be too simplistic and points out that medical knowledge is often limited, especially in chronic disease. It needs to be supplemented by biographical knowledge from the individual. He attributes the difficulties to high expectations of medicine rather than negative effects of medicine.

2.5 Illness narratives

The rise in chronic illnesses and the narrative turn in social sciences have coincided with a corresponding rise in illness narratives. Narratives about illness are available everywhere, from popular autobiographical accounts, novels and research studies to online support communities. They are used by practitioners, researchers and bioethicists to discuss issues in the particular, rather than as universal principles and therapists (Rauol et al., 2007). Illness narratives have been privileged in social science literature (Atkinson, 1997). There were a number of writers in the 1990s who explored how narratives gave people a different voice other than biomedicine to express their experiences (Frank, 1997, Hydén and Öruly, 2009)

Any illness will cause a disruption, but acute illness can cause a temporary re-assessment of our health, whereas chronic illness may cause a reassessment of the

relationship of our bodies to our world (Bury, 2005, Bury, 1982). Narratives have become especially prominent in chronic illness, one way that people cope with chronic illness is to incorporate it into the on-going autobiographical story of their lives (Hydén and Brockmeier, 2008).

There have been a number of different categorisations of illness narratives. One of the most influential frameworks is that developed by Arthur Frank. Frank described three types of illness narrative

- Restitution - in which the plot is about returning to previous health
- Quest - in which there is a journey to search for spiritual meaning.
- Chaos - in which there is no control and no meaning is possible. Life will never get better and it results in fear

(Frank, 1997).

Frank's illness narrative types are well developed and sophisticated but other researchers have found illness narratives that are more fractured (Hydén and Brockmeier, 2008).

2.5.1 Adjusting to chronic illness

The rise in chronic illness has led to concerns about both social consequences and also to studies of how individuals cope with illnesses (Bury, 2005). In the past illness was a normal part of the life cycle but now we value health. Chronic illness challenges the expectations of modern society, which include the government discourse of healthy ageing. The cultural expectations of a long and healthy life can lead to a sense of shock and fear when this is threatened.

In 1982 Mike Bury wrote his classic work on illness as biographic disruption about the impact of being diagnosed with, and living with a chronic illness. He describes three aspects of disruption resulting from a chronic illness. It can disrupt taken for granted knowledge, causing people to wonder what is happening. Secondly it can cause someone to have to rethink their biography and thirdly it can necessitate people having to think about and organise resources (Bury, 1982).

Any chronic illness can precipitate a change or adjustment in self-concept and identity, and indeed illness can become a focus of identity. Bury (2001) argues that people with chronic illness are faced with a change in identity and self-presentation that they need to deal with. People do not experience disease in isolation, they make sense of it in ways that are meaningful for themselves (Habermann, 1999). The consequences of chronic illness are not just physical symptoms and care needs but the possible threat to their sense of self, if things that are valued disappear and are replaced by a negative self-concept (Charmaz, 1983, Gillies and Johnston, 2004, Harman and Clare, 2006). There are a growing number of studies that contend that people make sense of an illness in ways that normalise it (Robertson, 2013)

Harman and Clare (2006) used a self-regulating model of illness as a framework in their study of adjusting to a diagnosis of dementia.

The stance each individual takes lies somewhere on a continuum between self-maintaining responses which are aimed at maintaining the prior sense of self, and self-adjusting responses, which involve acknowledging the changes dementia brings and integrating these into one's sense of identity

(Harman and Clare, 2006: 484)

The respondents did not remain static in one position but moved backwards and forwards along the continuum. The predominant themes were the desire to remain 'me', and the view that it will get worse.

Dementia is a chronic illness, like cancer in which mortality is made visible (Little et al., 1998). Kaufman (2006) describes the cultural work done by dementia at the end of life as making life ambiguous by blurring the boundaries between life and death. Although she does not use the concept of liminality this would seem to me to be an appropriate understanding of her argument. Liminality is a period of ambiguity in which boundaries are blurred (Turner, 1967).

The cultural expectations of a long and healthy life can lead to a sense of shock and fear when this is threatened. When liminality is used as an anthropological term, as a stage in a rite of passage, there is an expectation that people having been stripped of

one social status, enter a liminal state, then move on to another social status. In chronic illness people may stay in a liminal condition, instead of moving from a situation of illness back to one of health they remain in a state of illness. This has been described in people with cancer and with chronic pain (Little et al., 1998, Jackson, 2005). If we view the world as a system of classification people who do not fit because they have some ambiguity can become stigmatised (Douglas, 1966). Again this is seen within chronic pain and also in some mental health difficulties as people straddle boundaries (Jackson, 2005, Barratt, 1998).

The way in which dementia is framed will affect the treatment of people with dementia (Downs et al., 2006) and

‘there is growing evidence to indicate that at least some of the negative consequences of dementia may be mitigated or delayed by an approach to care that respects and supports each individual’s personhood’

(O'Connor et al., 2007: 122)

Personhood extends the model of dementia and has been widely adopted within dementia care (Hughes, 2011). The next sections discuss the emergence of the personhood debate and the on-going debates around identity and self in dementia.

2.6 The emergence of personhood

Definitions of personhood vary (Baldwin, 2009) and the relationship between personhood, self and identity is equally contested, with the terms sometimes being used interchangeably (Millett, 2011). I will concur with Millett and use the terms self and personhood synonymously in line with common parlance.

In 1997, Tom Kitwood, a social psychologist brought out his influential book *Dementia Reconsidered* (1997). Kitwood developed his understanding in response to the poor care that he identified in dementia practice, and he collected a number of his papers together in this book summarizing his approach to what he called the ‘person-centred care’ (Baldwin and Capstick, 2007, Kitwood, 1997, Leibing, 2006). He famously described personhood as

a standing or status that is bestowed upon one human being by others, in the context of relationship and social being. It implies recognition, respect and trust

(Kitwood, 1997: 8)

The place of interpersonal relationships and recognition by others is fundamental to Kitwood's view of personhood. He points out that the adverse effects of other people, and an inappropriate environment, result in what he calls malignant social psychology. He was influenced by the disability movement and distinguished between neurological impairment and disability, where difficulties for the person are caused by social and environmental factors (Kitwood, 1993, Baldwin, 2008, Kitwood, 1997).

In his formulation of dementia Kitwood appeared at times to accept the biomedical model, and his somewhat missionary zeal sometimes overtook his development of consistent theory. He placed the person with dementia at the centre of his model although his measure of well-being, dementia care mapping is carried out by the observation of people with dementia by others. His concept of person-centred care has been one of the most influential theories on the rhetoric of dementia care practice in the last few decades (Baldwin and Capstick, 2007, Harding and Palfrey, 1997). Although his concept of personhood is 'conferred by others' (Kitwood, 1997: 84), which ignores any agency for the person with dementia, it does highlight the potential for negative and positive effects of other people within care practice.

Clinical practice is beginning to offer an alternative narrative of dementia, from that of a medical problem, to one of personhood (Leibing and Cohen, 2006).

Personhood has 'provided a lens for conceptualising dementia practice and research for over ten years' (Bartlett and O'Connor, 2007: 107). The idea of personhood has been linked to good care within dementia practice (Leibing, 2006). The emphasis on psychosocial care may however neglect the need for physical care such as treating pain, which can become an issue especially as the disease progresses (Hughes, 2011). Kitwood's (1997) emphasis on the importance of relationships in preserving personhood can implicate carers. They may feel the person they knew has disappeared and an insistence on personhood can devalue their bereavement (Davis,

2004, Baldwin and Capstick, 2007). Although many care settings would now say that they provide person-centred care, what this actually means in practice fluctuates wildly (Hughes, 2011). Personhood can however still provide a useful concept for the consideration of dementia care and research.

The Centre for Research in Personhood in Dementia in Canada in collaboration with researchers in the UK has identified a framework for research focused on personhood in dementia that encapsulates current research and future directions for research on personhood.

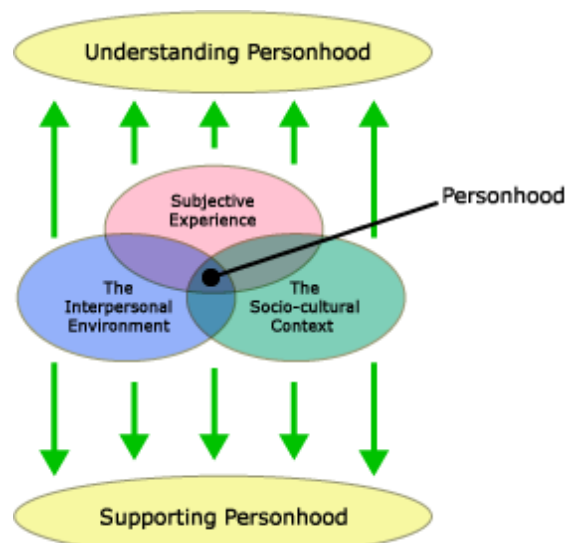


Fig 1 (O'Connor et al., 2007: p214)

The two objectives for research into personhood are understanding and supporting personhood. Within this perspective personhood has three facets (1) the subjective experience (2) the interpersonal environment (3) the socio-cultural context (O'Connor et al., 2007). This approach develops Kitwood's conceptualisation of personhood, taking forward the view of personhood as a process which occurs within the context of family and social care (Baldwin and Capstick, 2007). The emergence of personhood in clinical practice and other arenas allows for a different narrative of dementia to that of inevitable biological decline (Leibing and Cohen, 2006).

2.6.1 Self lost

Despite the increasing public awareness of dementia through campaigning and National Strategies, the picture of dementia can still be portrayed as bleak, with an

inevitable decline, resulting from neurological changes (O'Connor et al., 2007, Kitwood, 1997). Public awareness of dementia, supported by some of the national policies continues to sustain the view that people who have a diagnosis are a burden to both society and caregivers. People with dementia are depicted as deviating from the norm, their subjective experiences are marginalized. Early literature about carer burden contributes to the exclusion of people with dementia from the rest of humanity (Leibing, 2006). People in our society fear losing their minds (Kaufman, 2006) and people with dementia are commonly seen as victims of that worst fear. They may be depicted as 'shells', who have lost their self (Aquilina and Hughes, 2006, Beard and Fox, 2008).

Ballenger (2006) argues that the stigma attached to dementia is related not to behaviour but to our anxieties surrounding the boundaries between normal and pathological. It attacks the skills with which we present a stable self to other people, which is based on cognition. In her study of caregiver perceptions of hallucinations in people with dementia living in a care home, the caregivers interviewed by Cohen-Mansfield (2012) often attributed behaviour that they were unable to understand to hallucinations.

The literature addressing the relationship between people with dementia and caregivers is extensive (Boss, 2004, Garwick et al., 1994, Vass et al., 2003, Gillies and Johnston, 2004), but the main focus has until recently been the impact of a presumed loss of the self of the cared for person. At the same time carers may balance allowing change in the person they care for and wanting to preserve the person they knew (O'Connor et al., 2007, Balfour, 2006). A study of the effects on spousal relationships of Parkinson's disease and psychosis identified changes in identity as a main theme for carers in psychosis (Williamson et al., 2008).

Philosophical interest in dementia has increased over the past few years (Hughes, 2013). Hughes, Louw and Sabat (2006) edited an important collection 'Dementia: Mind, meaning, and the person' in which a number of dementia practitioners and philosophers were invited to explore issues of personal identity in dementia.

Dementia brings into question what constitutes selfhood and our understanding of selfhood informs our care for people with dementia.

Approaches to the loss of self in dementia range from Fontana and Smith's (1989) 'unbecoming of self', to social, cultural and bodily representations of self that reject a purely cognitive approach (Twigg, 2010, Hughes et al., 2006, Kontos, 2004).

Although we all change throughout our lives the fear in dementia is less of change than of loss (Lesser, 2006). The history of dementia as a disease is short, but the association of memory with identity are longer. The Enlightenment situated memory in the brain resulting in successful identity. John Locke promoted the idea that memory is essential for a rational person (Katz, 2013). If a Lockean view of identity that is dependent on the ability to remember oneself in the past and envisage oneself in the future is adopted, it may well result in loss of identity in dementia.

The Enlightenment was the age of reason, which informed understanding of mental illness. There were two main strands to this, the importance of reason that led to the promotion of an orderly society and technological solutions to human science, and the focus on the self. These led to the 'great confinement' and the rise of human sciences, resulting in the 'medical gaze' and also an requirement that people regulate themselves. (Foucault, 1977, Rabinow, 1984, Foucault, 1973, O'Farrell, 1989, Roberts, 2005, Bracken and Thomas, 2005). Reason was placed in opposition to madness, which diminished the possibility of subjective interaction between clinician and patient (Lovell, 1997)

The dominant narrative of loss in dementia privileges cognition, which is highly valued in Western society but it is not the only indicator of identity (Beard, 2004). A person with dementia is disadvantaged within a cognitive understanding of identity, resulting in them being understood as 'the demented other' (Naue and Kroll, 2008). Stephen Post (2000, 2006) describes a 'hypercognitive society' that stigmatises those with dementia as non-persons. He thinks that people have a potential for relationality that he calls a soul. He points out that society, in its care of persons with

dementia, demonstrates a different understanding from that of rationalist philosophers who classify them as non-persons.

People with dementia themselves have spoken of a loss of self. Robert Davis, one of the first people with a diagnosis to write of his experience, describes

The loss of self, which I was experiencing, the helplessness to control this insidious thief who was little by little taking away my most valued possession, my mind

(Davis, 1989: 91)

It is in the later stages that the uncertainty about identity is more evident. If spoken language becomes a problem it can become more difficult to know how to understand the unique identity of the person with dementia (Hughes, 2013). If we assume that people with later stage dementia lose identity there must come a point when it disappears. This is, however, difficult to reconcile with clinical experience and research evidence that memory and awareness fluctuate.

2.6.2 **Self found**

There is a wide range of opinion from people with dementia, carers, professionals and scholars about whether the self remains or disappears. The evidence from many people with dementia that has grown with the practice of earlier diagnosis, is that it is important to people that they are still themselves (Basting, 2003, Snyder, 2006).

Postmodernism has informed debates that challenge the concept of a fixed coherent self. Despite the rejection of realist concerns of truth, narratives from people with dementia are still treated with suspicion (McLean, 2006). The subjective experience of living with dementia has been marginalised by assumptions that people living with dementia are unable to speak for themselves. Despite this view there have been an increasing number of research studies about the subjective experience of living with dementia (Baldwin, 2008, Beard, 2004, Clare et al., 2005, Clare et al., 2006, Surr, 2006, Wilkinson, 2002, MacRae, 2010). Common themes to emerge from this work are coping, identity and loss of self. The concepts of self and identity are already challenged in the postmodern world, and dementia raises important issues for how

we see ourselves as a person. Tension is often expressed between the notion that identity changes throughout our lifetime, and attempts to maintain the self in dementia (Harman and Clare, 2006).

Identity can be usefully considered philosophically from two different aspects, that of quantitative or qualitative accounts. In a quantitative understanding, identity is defined in terms of its singularity and cannot be changed. We inhabit one body which is unique and we have our own social narrative. Taking this into consideration, it supports the growing importance of considering embodiment within discussions of dementia. Qualitative elements on the other hand are characteristics that make up a person and they can change. (Hughes, 2013, Millett, 2011).

People with dementia are writing less about the fear of losing self in the years since Davis (1989) wrote his book, and more about the fear of becoming a burden (Leibing, 2006). This may be related to policy discourses of healthy ageing. In some studies people with a diagnosis of dementia acknowledged changes, but not fear that they were losing themselves (MacRae, 2010, Steeman et al., 2011).

Much of the research into self and dementia has been done using interviews with people in the earlier stages of dementia who are still living at home (O'Connor et al., 2007, Surr, 2006). People in the early stages of dementia may be concerned at the prospect of loss of some aspects of self, but are evidently able to remember themselves in the past and envisage a future. They often express a desire for continuity within their day to day lives (Clare, 2003, Harman and Clare, 2006).

The loss of a **sense** of identity and self-awareness does not necessarily mean a loss of identity. People continue to exhibit different ways of being, and value things that have always been important such as music, even when verbal memories are eroded (Radden and Fordyce, 2006, Matthews, 2006). There is evidence that people with dementia retain emotional memory longer than semantic memory (Mills, 1997). McLean (2006) reminds us that coherent narratives carry a persistent emotional truth. Many clinicians would point to embodied interactions as indicative of identity (Hughes, 2013).

Lesser (2006) reminds us of the ‘boundedness of identity’, identity is connected to the past and future in the same way as we are bounded by life and death, one is not possible without the other. There is no sudden split between a then self and a now self, whereas there is an evident divide between life and death. However disabled a person becomes it is not the same as being dead and someone who is alive is not treated in the same way as a dead body (Matthews, 2006, Post, 2006).

Our bodies (also) define our temporality, especially our finitude. The body is the locus of past present, and future

(Thomas et al., 2004: 18)

More recently there has been a growing interest in embodiment in dementia. It broadens the debate about loss of self and assists in informing what Hughes (2011) calls our ‘human-person-perspective’, which is what we need to relate to the Other. Embodiment expands our resources for addressing selfhood from the biomedical emphasis on disease of the brain and the interactionist perspective of the social (Kontos and Martin, 2013). Kontos (2004, 2006, 2013) argues that selfhood is enacted in and through the body. She integrates Merleau-Ponty’s conception of self with Boudieu’s habitus to argue that even people who are severely affected by dementia exhibit selfhood in their corporeality. Merleau Ponty argues that the body is both subject and object to itself. Perception is not passive; it is interlinked with bodily knowing. Habitus comprises social and cultural understandings that function below consciousness. The body continues to make meaning despite cognitive impairment as our bodies have intention and understanding at a pre-reflexive level. (Kontos, 2004, 2006, Kontos and Martin, 2013, Lock and Strong, 2010).

Steven Sabat (2002, 2001) has written extensively about the way the performance and quality of life of people with dementia is affected by how they are positioned by others. He wrote a seminal paper with Harré in 1994 describing two aspects of selfhood (Sabat and Harré, 1994). Sabat has since developed the model to include three aspects of selfhood that he calls Self 1, Self 2 and Self 3 (Sabat, 2001, Sabat, 2002). He distinguishes between the way a person’s identity appears to others and the way people experience their own identity.

Self 1 is the sense of one's own personal identity, which includes continuity over time. For Sabat this self is evidenced by the use of personal pronouns and adjectives such as 'I', 'me' and 'mine' and is retained throughout life. It is a 'sense of self as a uniquely embodied being' (Sabat, 2001: 290).

Self 2 consists of our unique mental and physical attributes, some of which remain over time while others may change. A diagnosis of dementia belongs in this self along with our beliefs, including beliefs about our attributes. If someone is given a diagnosis of dementia then their beliefs about the elements this brings are in Self 2.

Self 3 comprises socially presented selves, meaning there can be multiple Self 3s including various different roles. Self 3 is the self that is dependent on the co-operation of others; one cannot be a teacher unless there are students who accept you as such. This self is most vulnerable in dementia as someone may be positioned by others, according to the negative aspects of dementia seen in Self 2. This can affect the Self 3.

Sabat's theory of selfhood starts to address criticisms that a purely social view of selfhood misses out the embodied self (Kontos, 2004).

In conclusion there is no consensus about the self in dementia but dementia challenges philosophy in the same way that philosophy can challenge assumptions about dementia (Hughes et al., 2006). Research and clinical evidence has shown that a sense of self awareness is retained in early dementia and that for the person with dementia it is important that they are recognised as individuals with a unique identity.

As Sabat's conceptualisation of Self illustrates, despite the modern view of the individual self, people do not live alone, they live within relationships. These include close intimate relationships and relationships with other members of society and they all impact on our experiences.

2.7 Living in relationships

Fontana and Smith (1989) argue that some carers who assume the role of agents for people with dementia, as if their old self were still there are deceiving themselves. Balfour (2006) in his exploration of the unconscious processes for the person with dementia describes the carer as a ‘container’ who reflects the world of the person with dementia. Mills (1997) in a longitudinal study of narrative identity of people with dementia, which she defined as requiring a life history and memory, argues that narrative memory and narrative identity faded for some people as their illness progressed. She suggests that

They had bequeathed their narrative to another....In this sense, therefore the personal narrative of dementia sufferers is never lost

(Mills, 1997: 695)

The tension for caregivers between maintaining the identity of the person with dementia and grieving for the loss of shared memories and a relationship can result in guilt.

The development of personhood within the dementia debate focused predominantly on the experience of the individual. This is understandable given its naissance as a response to poor care within institutions, but over the past decade there has been a recognition of the place of relationships (Hellström et al., 2005). People live within a context of relationships and we should move beyond a person-centred approach to a relationship-focused approach (Nolan et al., 2004). A number of recent studies have focused on how a sense of self is co-constructed within relationships (Clare and Shakespeare, 2004, Hellström et al., 2005). Taylor (2008) highlights the perception of others that the self is lost in dementia if the person is unable to recognise the carer. Carers are frequently asked ‘does she recognise you’ as if a negative answer to this question absolves us from recognising the person with dementia. The narratives of others should not be viewed as privileged over those of people with dementia, but as assistance in setting the context by providing factual information such as dates and characters (McLean, 2006). Positioning memories outside of the self extends the boundaries of the self to include relationships (Leibing, 2006). The notion of the

autonomous person has been challenged from ethical positions (Post, 2006) including both cultural (Tsai, 2009) and feminist perspectives (Gilligan, 1982, Barnes, 2012). Ethics of care perspectives will be discussed in more detail in the next chapter.

2.8 Socio-political discourses

People are living longer and the drive within the public health agenda is towards healthy ageing. Ageing well is active ageing, the goals of which are maintaining cognitive, physical and social capacities (Williams et al., 2012). In Scotland people with dementia are being consulted in government policy about dementia. Socio-political discourses continue to be disadvantaging, however, often framing dementia in a negative way.

2.8.1 Epidemic

There were 71,000 people in Scotland with dementia in 2010 and this was forecast to double within the following 25 years (Scottish Government, 2010). Dementia predominantly, although not exclusively, affects older people, with a common co-morbidity associated with ageing, and people with dementia are significant users of health and social care services resulting in high expenditure. (McCrone P et al., 2008). It is described as apocalyptic and challenges our ideas of what matters as identity (Kaufman, 2006).

The prevailing paradigm of dementia within Western society is often one of a degenerative disease that poses an increasing socioeconomic problem for society (O'Connor et al., 2007, MacRae, 2010). Dementia has become a more pressing social and political issue because of demographical predictions of the expanding growth of older people within society (Naue and Kroll, 2008).

There is a growing literature on how dementia has been constructed as a global epidemic (Fox, 1989, Cheston and Bender, 1999). The metaphoric description of dementia as an epidemic plays on people's fears of dementia as a devastating force that destroys the self of the person with dementia, as well as people with dementia as overwhelming consumers of social and economic resources (Johnstone, 2013). George and Whitehouse (2012) compare the metaphors used, describing a 'war on

Alzheimer's disease', with those describing a war on terror following the events of 9/11 in New York. Dementia has become the evil enemy in order to increase research funding (Beard and Fox, 2008) yet despite improved financial support, a cure has not been found (George and Whitehouse, 2012).

Dementia constitutes a threat to society because it occurs in an ageing body that does not conform to the ideals and aspirations of a healthy body. Within Western society ageing is often associated with deterioration and death. People with dementia and older people are understood in terms of loss rather than as valued and equal members of society despite the conflicting agenda of active ageing. A diagnosis can be dependent on culturally and socially unacceptable behaviour (Harding and Palfrey, 1997).

2.8.2 Self advocacy

James McKillop (2002) described a possibility available to him following his diagnosis of dementia in 1999

I could have kept blundering around my shrunken world
deeply depressed, as I had been decisively excommunicated
from a misunderstanding society

(McKillop, 2002: 110)

He did not accept this option but instead went on to found the Scottish Dementia Working Group (Scottish Dementia Working Group, 2013). The practice of dementia care and research is changing focus to one of person-centred care. Clinical practice is beginning to offer an alternative narrative of dementia, from medical problem, to one of personhood (Leibing and Cohen, 2006). Research is addressing the subjective experience of people who have dementia alongside that of carers. The belief that people with dementia are unable to discuss their experiences has been challenged (Mills, 1997, Clare et al., 2005, Wilkinson, 2002).

The opening article in the first edition of the research journal *Dementia* was written by a woman with dementia (Sterin, 2002). People with dementia have begun to speak about the impact that a label of dementia has made to the way society sees

them (Bryden, 2005, McKillop, 2002). Organizations such as Alzheimer Scotland and Alzheimer's Society UK, which were established by carers in the 1970s, now have active members with dementia. Campaigning groups run by people with dementia such as Scottish Dementia Working Group (Scottish Dementia Working Group) and Dementia Advocacy Support International (DASNI) (Dementia Advocacy and Support Network International) have been established. They have begun to address issues of power relationships and citizenship within dementia (Bartlett and O'Connor, 2007). People with a diagnosis of dementia are utilising technology and writing blogs (Swaffer, 2013, Taylor, 2013b). The 2012 Alzheimer Europe conference saw over fifteen people with dementia attending, many of them giving presentations. At this meeting the European Working Group of People with Dementia was founded (Alzheimer Europe, 2012).

People with mental health problems have also become more active in challenging the narrative that they are unable to speak for themselves (Hornstein, 2012, Roe and Davidson, 2005). Of particular interest with regard to this study is the Hearing Voices Movement, which is critical of psychiatry's traditional classification of auditory hallucinations. Groups have been established throughout the United Kingdom where voice hearers support each other and challenge traditional psychiatric practice (Hearing Voices Network, 2013).

Both UK and Scottish government are committed to partnership working with increased public participation at policy and individual levels within health and social care.

Patients and carers are after all, the real experts in what it feels like to receive care from NHS Scotland. Our task is to listen to them, think afresh about the ways in which we involve and engage them in shaping their care and work in new and different ways, which challenge traditional boundaries, both within and between organizations.

(NHS Scotland, 2007: 49)

Importantly Scotland's first Dementia Strategy was published in 2010 and it has just been updated at the time of writing in 2013 (Scottish Government, 2010). The

Scottish Dementia Working Group was consulted in the development of the strategy and this represents significant achievement in the advocacy movement.

2.8.3 Citizenship

O'Connor et al. (2007) identify a gap in research into understanding the implications that the wider policy, institutional and cultural context have on the subjective experience of dementia and personhood. There is an emergent body of work that is beginning to address the intersection of cultural setting and subjective experience (O'Connor et al., 2010, Hulko and Stern, 2009). Although the contribution of the concept of personhood into understanding the discrimination suffered by people with dementia is acknowledged, it has been criticised as an apolitical concept. This has resulted in an increasing interest in the concept of citizenship (Bartlett and O'Connor, 2007, Bartlett and O'Connor, 2010).

2.9 Evidence in health research

Before the introduction of evidence-based medicine, medical procedures were condemned for being based on personal preference or custom (Lambert, 2006). The gold standard in clinical biomedical research is now the randomised control trial. This supremacy has not, however, gone uncontested. As Bracken and Thomas (2005) point out, the best treatment is decided on by committee rather than the circumstances of the individual patient. This view of science and research assumes the objectivity of science that has been challenged by a multiplicity of theorists and researchers (Haraway, 1988, Latour and Woolgar, 1986, Harding, 2008, Law, 2004).

Murray, Homes and Rail (2008) assess evidence based medicine from a Foucauldian perspective, believing that it threatens the clinician-patient relationship, and is of limited use to the individual patient. Positivism dominates but clinical practice is often about uncertainties and storytelling, which raises issues about whose knowledge is privileged (Miller and Crabtree, 1998). There are competing political drivers in healthcare. Alongside the requirement to practice evidence-based

medicine is another agenda calling for more public participation. Participation calls for user control, collaboration and consultation, which requires a shift from the power of the professional (Nolan et al., 2007). Evidence based medicine is seen by some as a threat to the clinical judgement of the individual doctor and by others as an increase in power and authority for a collective professional body (Lambert, 2006). Views of doctors are traditionally seen as more realistic than those of the patient in what Becker calls a 'hierarchy of credibility' (Becker, 1967: 241) . Nolan et al. (2007) argue that the service provider has factual knowledge whereas the knowledge of the service user is situated knowledge.

Thornhill et al (2004) call for psychiatric practice to catch up with academic theorizing by listening to multiple realities. They point out that there is more than one way to understand experiences and that post-modernism has rejected the idea that there is a single answer. Evidence-based medicine does not engage with social and cultural issues despite their impact on health status, although many individual clinicians take into account in their practice (Lambert, 2006).

Bracken and Thomas (2005) would ascribe different realities of psychiatric understanding to the split between academic and clinical psychiatrists, arguing that academic psychiatry has retained its 'scientific' underpinning whereas many clinical psychiatrists, in the move to community provision of services are engaging with user groups. My experience concurs with the clinical practice described by Hughes (2011) of working with people with dementia within context, although I accept that this may be an individual experience.

A different way of understanding these tensions is provided by Frank (1997), he argues there is a clash between administrative and cultural change, and an older modernist assumption of the professional expertise and the rational individual.

Mol et al (2010) point to the way that the care sector often separates care into interventions and relational work. The role of clinical trials is to establish whether an intervention constitutes good care, relational aspects of care are measured by medical ethics. As the next chapter will explore further, they argue that the practice of care

involves local solutions to particular problems rather than generalised disembodied principles.

The final section returns to a personal view of care with a story of my relationship with my mother.

2.10 View from a daughter

My mother was admitted to a care home a few years before I began this study. She had Parkinson's and was finding it more difficult to cope at home, so decided to enter full time care. I am not sure if she ever had dementia or whether her Parkinson's caused her symptoms but whatever the medical cause, the effect on me was the same. I could probably explain the aetiology of her behaviour in a medical way but that would not be enough to account for the experience.

Visiting my mother in her care home was becoming more difficult. Her multiple health problems, which had begun with Parkinson's had led to some memory impairment and episodes of paranoia. I knew this was a common side effect from her medication. I sat with her in the sitting room struggling for conversation.

The care home was having a fete; it was busier than usual. The staff were wearing their own clothes rather than their blue uniforms. They bustled in and out, organising different stalls. A welcome relief from the usual routine, they had given up their day off to raise funds for the home. A young boy around twelve arrived looking a little awkward. He was the son of a nurse, roped in to help out, or maybe just refused permission to stay at home alone. My mother suddenly perked up 'you need to watch that boy, he steals' she announced. Her voice, normally quiet and slurred, changed by Parkinson's, rang out unexpectedly clearly across the sitting room.

I sat still for a second, embarrassed; I could see she was still attentive. I didn't want her to continue with her tirade and blurted out 'you're a foul old woman'. She looked at me, a smile, breaking through the mask of the disease. I felt a flash of recognition for the person who was once my mother and the argumentative

relationship that we had. Then the embarrassment again. These people knew what I did for a living; I wanted to tell them that I do not speak to my patients like this.

As a clinician I believe that people with dementia do not lose their self, but as a daughter I was more conflicted. My mother had changed; I was sure of that, she liked children and would never previously have reacted so aggressively towards this boy. I attempted throughout the period she spent in the home to tell the staff something of who she had been. It was important to me. Despite living 200 miles away, I tried to do all the right things when I visited. I took in photographs of her and told them about her earlier life. Our interaction in this incident was no different to our previous communication style, but its meaning for me was very different.

An ethics of care framework acknowledges that care can be part of an on-going relationship and does not ignore the emotional aspect of care (Barnes and Brannelly, 2008). As Davis (2004) points out the relationship between myself and my mother began before her illness. My way of being with my mother was part of a pre-existing narrative and whatever Kitwood (1997) may say, her memory problems and her paranoia changed that relationship.

Since her illness our relationality had altered and this was what I found problematic to manage. I found it difficult to create a new kind of relatedness. I concur with (Lambek, 2007) that for me remembering was also a moral and ethical practice. My need to inform her care home of her past was a desire not to let her history begin in the present, as a woman who was dependent and unpleasant. I was creating different selves for my mother each time I told the story, and continue to do so. I am however silencing her telling of her self, and her subsequent death has meant her ability to tell her own fractured self has been silenced for good. I do however believe that it supports my understanding of personhood as existing as part of a bounded life, which provides an ethical approach for me. People with dementia remain people whatever stage of the illness they experience.

My struggle was about the ambiguity of my relationality and my emotional knowing. Liz Stanley (1993) describes this struggle of knowing and not knowing her mother.

She was sure that somewhere her mother as she had known her remained but was hidden beneath a different self.

2.11 Conclusion

As Rauol et al. (2007) claim narratives of illness can appear at different levels - individual, groups, professional and societal. Each will privilege a different aspect over others. This chapter has addressed the main discourses that are relevant to this study. People with dementia who hallucinate are often cared for by mental health teams, so the predominant narrative of dementia as a disease, and some of the implications of this were discussed. We can tell the story of our self or it can be told by others. The story that is told will impact on the way people with dementia are viewed by society, and by carers, both family and paid.

Hallucinations remain elusive; each of the discourses of dementia misses something out. If as Julian Hughes says dementia is a ‘conceptual mess’ (Hughes, 2011: 17), there needs to be another way to describe something that is messy ‘because simple clear descriptions don’t work if what they are describing is not itself very coherent’ (Law, 2004: 2). Socio-political stories of dementia may conflict with the stories of individuals with dementia but the differing multiple stories may all have relevance to experiences of care. The next chapter discusses a number of social science theories that enable us to think in different ways about hallucinations and dementia as ‘messy objects’.

3 Situating knowledge

I float on the sea of knowledgeI sail on the surface of
understanding, a flicker here, a silence there

(Jamie, 2012: 17)

This haunting description comes from an essay by the poet Kathleen Jamie describing a journey to the Arctic. She manages to verbalise the difficulties of knowing the intangible in ways that distil its essence.

3.1 Introduction

In the previous chapter I outlined a variety of different discourses of dementia. Each of the conceptual models of dementia can be clinically useful but they have different values (Hughes, 2011). This chapter introduces the theoretical lenses through which diverse discourses can be understood and that shaped the research.

The theoretical work that has influenced me and will be discussed here comes from three main fields. Firstly it comes from science, technology and society studies (STS), especially those studies that address the concept of reality (Law, 2006, Law, 2004, Law et al., 2013, Haraway, 1988) and the heterogeneity of medicine (Mol, 2002, Mol and Berg, 1994, Moser, 2011). The second influence is the concept of liminality that originates in anthropology, but has recently been used to inform other areas such as illness and disability (van Genneep, 1960, Turner, 1967, Adam, 2004, Blows et al., 2012). Lastly I will discuss the work of feminist care ethics (Gilligan, 1982, Tronto, 1993, Barnes, 2012).

Care involves the network that continues to make small adjustments to enable things to work rather than being about cure. It utilises different knowledges that are fluid (Moreira, 2010). Mol (2008, Mol et al., 2010) describes the continuous fine tuning involved in care practice as ‘tinkering’. In this chapter I introduce a number of concepts to argue alongside Law, Mol and others from STS that multiplicity is integral to care practice.

3.2 A view from somewhere¹

Many people who undertake a doctoral study talk of it being a journey. This chapter acknowledges my journey to find a lens that could inform my research approach. It also needs to reflect my understandings of hallucinations and dementia.

Back reminds us of the need to integrate theory and empirical enquiry

The usefulness of theory lies in its ability to invite us to ask different questions of the social world

(Back, 2007: 16)

I am studying something that is ephemeral: hallucinations in dementia can appear and disappear. They are like the family resemblances studied by Jennifer Mason (2011), difficult to pin down and not conforming to any rules of temporality or regularity. This immediately poses difficulties for my study as it disrupts our common sense ideas of reality and truth.

The world is not homogenous and individuals deal with complexity and contradictions daily. There are different ways of knowing and different stories that can be told, as we saw in the previous chapter. I am aware of and even comfortable with this in clinical practice. I have often been in the position where I am unable to give a definitive answer that other people have wanted from me. The individual trajectory for a person with dementia is not predictable. Law (2006) makes the point that it is easier to achieve coherence in theory than in practice.

Feminism methodologies have changed understanding of knowledge and influenced the way research is conducted. Feminist researchers have embraced reflexivity in questioning the nature of knowledge claims and research relationships (Ribbens and Edwards, 1998, Doucet and Mauthner, 2002).

¹ This expression was used by STENHOUSE, R. 2009. *Unfulfilled expectations: A narrative study of individuals' experiences of being a patient on an acute psychiatric inpatient ward in Scotland*. PhD, University of Edinburgh.

If, as I would argue, knowledge is situated and contextualised then a reflexive element in knowledge construction is inevitable. Reflexivity recognises the role of interpretation in all knowledge production, disputing the idea that there can be any true mirroring of facts, as well as acknowledging the importance of interpretation within the research (Alvesson and Skoldberg, 2009)

Although not always referred to explicitly as reflexivity, the *project of examining how the researcher and intersubjective elements impact on and transform research* has been an important part of the evolution of qualitative research

(Finlay, 2003: 4 italics in original)

Ethnographic texts are no longer prefaced as ‘objective’ descriptions of unknown communities written from the perspective of a stranger. It is now commonplace to have studies of familiar communities that acknowledge the contribution of the interaction of the researcher in the field towards knowledge production (Coffey, 1999). Reflexivity involves us owning that we are part of the social world that we study. We bring knowledge with us, which may be flawed but can become part of our inquiry (Hammersley and Atkinson, 1995). Subjectivity is inescapable within research starting with the decision of what to study and continuing all the way through to the presentation of findings. Placing the researcher in the context means making explicit how and why the research was carried out (Stanley and Wise, 1993). Feminist researchers in particular have identified the dilemmas that can arise within research relationships, reflecting especially on power differentials (Mauthner and Doucet, 2003, Ribbens and Edwards, 1998). My writing is partial and situated, where I am situated impacts on the knowledge I create (Ribbens and Edwards, 1998). However much I as a researcher wish to adopt an inclusive approach, inevitably I decide what is written and how. People with dementia remain a marginalized voice within society. They may be perceived as vulnerable therefore the question of power in research involving them is an inevitable consideration of this study. My study also involved relatives and professionals and a reflexive approach to my relationships with both these groups was equally important and will be discussed in the next chapter.

It has been a struggle for me to reject a search for ‘objective’ knowledge despite the clinical experience that allows me to live with complexity and contradiction. Neilsen captures the emotional conflict well when she writes

I believe deep down that our positivist souls are still attracted
to knowledge as answer, as firm ground

(Neilsen, 2002: 210)

My subjectivity shapes the way I have constructed knowledge. Haraway (1988) highlights the dichotomy that exists between the pole of objectivity and that of relativism. She uses the term ‘situated knowledge’ as a way to reclaim an engaged view from somewhere.

3.3 Partial and situated knowledge

We live with partial connections and contradictions all the time and denial of this leads to what Haraway (1988) calls ‘the god trick’. This is the supposition that we can assume a view from everywhere, an all-knowing, objective view of the world. Haraway calls this view a self-delusion. Our knowledge is never complete but always partial. All knowledges are partial and situated within a context. We cannot know and represent everything. There is no single, absolute and authoritative truth out there waiting to be discovered. This is not a problem unless as Haraway (1988) argues we assume to speak from an objective truth, to perform ‘the god trick’.

If we can live with partialities and contradictions, and I would argue that medicine does this all the time in practice, then we need to find methods in research in which we can live with this mess without ignoring or ‘othering’ it (Law, 2006, Law, 2004). Law (2004, 2006) argues that it is impossible to know the world, including describing it, because whenever we bring something into presence we unavoidably leave something out. Presence is what is made present, which inevitably implies absence. If we do not pretend that we are seeing everything it is not problematic. Ignoring the other, means we pretend that there is a coherent story in our research and that the world is not messy.

Method does not just represent social life, according to Law, method is performative, it produces realities, making visible some aspects of reality out-there and making others invisible. Methods have a double social life, they are shaped by the social world and they also help to shape it (Law, 2010). Recent understanding of the practice of social science is that it does not just describe the social world but contributes to making and remaking it, it can contribute to the world it wants to make. Law and Urry (2004) cite the analysis of deviance that has led to attempts to decrease stigma in society. This social science concept achieved wider societal understanding, and appreciating the consequences of labelling on people resulted in changes in social policy. Methods inevitably make assumptions about the social world and reproduce them (Law, 2010). I am assuming here that there is a group of people who have dementia, and they have realities that differ at times from consensus reality and are called hallucinations. I have this understanding based on my experience as a mental health nurse and this led to my desire to explore this topic.

Although life is messy, modern society does not like disorder (Ingold, 2010). The complexity and clutter of life cannot be understood through universal abstractions, but needs to be situated within specific contextual settings (Law, 2004, Mol, 2002, Haraway, 1988, Barnes, 2012).

This study is not just about how we know the social world of people with hallucinations and dementia, but also how they know reality. How then can I begin to understand the impact of hallucinations on the people with dementia who live with them, those closest to them and the mental health professionals who work with them? People in general assume that our perception of the environment leads to an unmediated independent reality, but this is ambiguous. Merleau-Ponty (1962) illustrated that there is an element of creativity involved in our interpretations, using examples of well-known optical illusions.

Hallucinations, which may be common place to a clinician, may startle someone who is unfamiliar with these strange experiences. They may well be described by the person experiencing them in a matter of fact way. Hallucinations challenge the idea of a shared reality but people who hallucinate do not always see or hear something

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without an external stimulus. My experience of hallucinations in dementia is that it does not conform to a narrow textbook definition of hallucinations. I concur with Ffytche's view

Many patients who on some occasions 'see things that are not really there' will on other occasions 'see real things incorrectly'

(Ffytche, 2004: 16)

Boundaries act as barriers that define knowledge practices and concepts (Fox, 2011). Situated knowledge and messy reality challenge these barriers and the following section discussed some of the ways in which unstable boundaries can be understood.

3.4 Boundaries

Traditionally Western thinking has created dichotomies such as self/other, mind/body and male/female (Haraway, 1991). Boundaries protect, they keep out non-coherence (Law et al., 2013). Borders are associated with modernity but their purity is being increasingly challenged by postmodernity, feminism and social studies of science. We saw in the previous chapter that a diagnosis of dementia is evaluative, 'there is no hard scientific boundary between disease and normality' (Hughes et al., 2006: 2), but attitudes towards dementia can have a critical impact on the way society judges people with a diagnosis.

Rational/irrational can be just such organising categories that can result in negative judgements of people whose realities may not coincide with our own. Using binary distinctions to aid understanding, we can forget that dichotomies simplify and iron out the ambiguities: the wider and more inclusive the category, the more that is eroded from it. These dichotomies create boundaries that have been contested in a number of ways.

The next sections will describe three of these challenges, those of boundary objects (Star and Griesemer, 1989, Fox, 2011), cyborgs (Haraway, 1991), and messy objects (Law and Singleton, 2005).

3.4.1 Boundary objects

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entities that enhance the capacity of an idea, theory or practice to translate across culturally defined boundaries

(Fox, 2011: 70-71)

The concept of boundary objects was developed by Star and Griesemer to describe how different groups, amateurs, professionals and administrators collaborated to establish a Natural History Museum. Boundary objects facilitate the different understandings and objects between interested groups to enable a mutual understanding between social sites (Star and Griesemer, 1989). They can allow different groups to share meaning and learn about the others' perspectives. They work either because of an intrinsic property of the object or because of a specific context (Fox, 2011). They need to have a receptive audience, as Fox (2011) describes in his historical analysis of the way theories of infection were translated into practice in operating theatres. Surgeons accepted the less convenient aseptic technique rather than antiseptic. Their approval was based not on expedience but on both contemporary medical understanding, and their equating of antisepsis with an accusation of impurity on the part of surgeons. Sterile clothes and instruments were acceptable boundary objects as they allowed the doctors to maintain a role as healer rather than polluter. Boundary objects act to blur boundaries and enable communication, but as Mol points out the different regions remain (Fox, 2011, Mol, 2002).

3.4.2 **Cyborg**

Donna Haraway's polemical Cyborg Manifesto, which was initially written in 1985, has been much cited. In challenging the feminist and socialist theories of the time, she utilizes the metaphor of the cyborg to deconstruct the ideas of inflexible boundaries. A cyborg is a hybrid of organism and machine; Haraway describes it as social reality and science fiction. She was critical of the Marxism and feminism of the time, finding them problematic because they were unable to hold contradictions together. In their desire to achieve political and social change they eliminated difference, using the same language of dualism as Western traditions. The cyborg enjoys the blurring of boundaries and uses its partiality to destabilize them giving us new possibilities. It is a collection of partial connections (Law, 2004). It holds

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together opposing concepts such as human and machine that are part of our social reality in the twentieth and twenty-first centuries. They are vital but do not go on to make a new larger whole. Haraway's cyborg addresses materialities, providing a way of thinking that acknowledges material-semiotic networks. It is a way of thinking about materials that treats them as having a relational effect. Everyday medical practices such as the use of technological implants into the body are now commonplace, but can still disquiet us. (Haraway, 1991).

Lapaum et al (2012) use a cyborg ontology to theorise the nursing practice that occurs between 'person centred care' and technological knowledge and can be integral to modern care. I love the playful approach of Haraway which allows the freedom to enjoy messy borders. The final sentence of the Cyborg Manifesto 'I'd rather be a cyborg than a goddess' feels liberating in a world that can still be constrained by dualities that do not reflect practice, a world that as Law (2006) argues tries to use something ordered to describe mess.

3.4.3 Messy objects

A seemingly straightforward request to investigate the trajectory of patients with alcoholic liver disease led to an unexpected difficulty for the researchers Law & Singleton (Law and Singleton, 2005). They described their object of concern as a messy object, accounts given by interviewees could be diverse and difficult to map onto each other. The reality of the alcoholic liver disease in the textbook is very different from that of a general practitioner for whom it was the social consequences of living in a deprived area. Instead of something that they thought would be easy to trace, they found that it was elusive. It is enacted in multiple sites, from a textbook definition where it is located in the body, to in a non-statutory agency. Although what people said during interviews was not irrelevant it did not fit a narrow definition of alcoholic liver disease.

They describe two possible explanations for the appearance of this messy object, both of which they reject. These accounts are firstly that their research approach is inadequate, or secondly that the NHS facility that commissioned the research is managing alcoholic liver disease badly.

Smoothing out the mess does not allow them to know the object, which has ‘multiple and discontinuous absences’ (Law and Singleton, 2005: 350, Law, 2006, Law, 2004). A messy object is ontologically complex.

‘a shape-changing object that, even more misleadingly, also changed its name’

(Law, 2004 :79)

This notion of a shape shifting object resonates with my experience of working clinically with people with hallucinations. It fits with Gillett’s (2004) description of hallucinations as like a ‘will-o-the-wisp’. Law and Singleton (2005) make the point that although they had difficulty with alcoholic liver disease changing in their study, the fluidity was managed well by the professionals they interviewed.

I made a decision early on to use the word ‘hallucinations’ in my inclusion criteria. I left the decision as to whether participants fitted this description to mental health nurses. Despite my reservations that hallucinations as a diagnosis has an ephemeral nature, I was reasonably sure that other mental health nurses would share a similar understanding to me. The boundaries between hallucinations and other perceptions are not clear cut especially within dementia. Regardless of my misgivings, the category of hallucinations still exists within mental health practice so cannot be ignored, but needs to be approached with caution. Assumptions of clarity will not result in coherent reality. Law and Singleton (2005) argue that we need to tolerate ambiguity. The anthropological concept of liminality explores a time and space that accepts and is constituted by ambiguity.

3.4.4 Liminality

People with dementia can be viewed as being on a threshold. There are fuzzy boundaries between normality and pathology as well as between hallucinations, illusions and misperceptions. One way to understand these ideas is through liminality. The word ‘liminal’ comes from the Latin limen meaning threshold. It was a term developed and used in anthropology to describe a stage during ceremonial rites of passage. Van Gennep (1960) concluded that there are three stages during rites of passage, when someone transforms from one status to another, a preliminal or

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separation stage, a transition and a return to a new status (Turner, 1967, Felde, 2011).

Turner (1967, 1979, 1977) developed the understanding of the transition or liminal period to evaluate better the work he had done on the ritual process. He applied the understanding to both small scale and larger societies believing that despite the decline in importance of religion, ritual process had spread to other areas of socio-cultural life. He described the liminal state as 'betwixt and between' (Turner, 1967: 111). The transition that occurred, according to Turner is a process or a transformation. The person in the liminal state is neither one thing nor the other; they have left behind one status and have not yet moved on to the next, although they may exhibit aspects of both. Liminality is not a static state but a confusion of usual categories, ambiguity and disorder. It can be either a positive or negative experience, as society bestows on the person a specialised status. It does not necessarily isolate people, they may also experience camaraderie in their seclusion that allows them to be themselves without having to conform to institutional roles (Turner, 1967, Jackson, 2005). Although limen means threshold, Turner (1977) contends that it can be prolonged, and using the example of monks, he argues that it can even become a way of life. This thinking has been expanded to encompass understandings in the field of chronic health.

3.4.4.1 Chronic illness and liminality

Liminality has been used in health in recent years to theorize conditions where the person feels healthy but has clinical signs of abnormality, as in the management of raised cholesterol (Felde, 2011) or an abnormal cervical smear result (Forss et al., 2004). It has also been used in approaches to chronic health problems like chronic pain (Jackson, 2005) cancer (Little et al., 1998) and mental health issues (Warner and Gabe, 2004, Barratt, 1998).

In the past illness was a normal part of the life cycle but now we value health. Chronic illness challenges the expectations of modern society which include the government discourse of healthy ageing. The cultural expectations of a long and healthy life can lead to a sense of shock and fear when this is not what happens.

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Dementia is a chronic illness, like cancer, in which mortality is made visible (Little et al., 1998). Kaufman (2006) describes the cultural work of dementia at the end of life, as making life ambiguous by blurring the boundaries between life and death. Although she does not use the concept of liminality this would seem to me to be an apposite understanding of her argument.

When liminality is used as an anthropological term, in rites of passage there is predominantly an expectation that people having been stripped of one social status, enter a liminal state and then move on to another social status. In chronic illness people may stay in a liminal condition. Instead of moving from a state of illness back to one of health they remain in a state of illness. This has been explored in people with cancer and those experiencing chronic pain (Little et al., 1998, Jackson, 2005). If we view the world as a system of classification, liminal phenomena do not fit and so people can become stigmatised. Again this is seen within chronic pain and also in some mental health difficulties, as people straddle boundaries (Jackson, 2005, Barratt, 1998)

3.5 Common sense reality

Reality has preoccupied philosophers for centuries but it is the common-sense assumptions of reality that are relevant to this discussion and are addressed in the theories of John Law and Annemarie Mol.

Law is a sociologist who has done much interdisciplinary work especially in the field of science, technology and society (STS) that focusses on the impact of society on science and technology. This thinking has led scholars like Law to challenge the common sense attributes of reality (Law, 2006, Law, 2004). Law ascribes five attributes to common sense reality

- Primitive out-there-ness - a primitive sense that there is a reality out there that is beyond ourselves
- Independence - what is out there is independent of our actions
- Anteriority - what is out there precedes our attempt to know it
- Definiteness - the something that is out there is not vague

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- Singularity - the world is a single material reality that is more or less shared. This is not the same argument as that there are different perspectives on a single reality

(Law, 2006: 6-7)

The primitive sense of out-there-ness is the only assumption he accepts. We tend to take reality for granted; it informs how we live our day to day lives. Our common-sense reality advises much science and social science research (Law, 2006). We are taken aback by hallucinations that challenge our acceptance of a shared external world. A diagnostic criterion for hallucinations takes for granted a single external reality that the person who hallucinates sees or hears wrongly, resulting in a reality disjuncture.

Pollner contends that reality disjunctures are ‘contradictory experiences of the world’ (Pollner, 1975: 411). When any difference in experience occurs there is an ‘ironicizing of experience’, the irony happens when there is a realization that the initial perception is wrong. This can become apparent either as a result of intrapersonal or interpersonal reconsideration. People realise for themselves that their initial view was wrong or someone else points it out to them. A reality disjuncture occurs when a choice is not made about which version prevails, and one side is portrayed as faulty. They often result in a vicious circle, as resolution is not possible by simply looking at the world, because this is how the disjuncture occurred in the first place. The decision to act on a particular version of reality results in the discreditation of the other version. The discreditation is commonly applied to the experience of people who hallucinate and can result in stigmatisation

The argument from social studies of science within the last quarter of the twentieth century that science is not neutral, has led to greater interest in exploring how scientific realities are made in practice within laboratories and medical science (Haraway, 1988, Latour and Woolgar, 1986, Moser, 2011). Medicine is a lived reality not just something that happens alongside the life world (Moser, 2011). John Law and Annemarie Mol among others address the multiplicities that are enacted in

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practice. Different discourses may emerge from different approaches, which is why a situated approach to knowledge is singular and specific, but includes multiplicity (Law, 2004, Mol, 2002).

3.6 Enacted realities

Enactment of realities allows for multiplicity and tensions. Law and Singleton (2005) argue that ‘messy objects’ can be addressed using an epistemological or an ontological approach. Law defines ontology as

The branch of philosophy concerned with what there is, with what reality out-there is composed of

(Law, 2004: 162)

Epistemology is concerned with how we acquire knowledge. In an epistemological approach, variations are explained as different perspectives of a single knowable object. There is a flexible reality that occurs in the transactions where different groups meet. The aim of knowledge is to identify the real object hidden at the centre, which has distinct meanings for different people. An ontological approach argues that instead of multiple interpretations, we should consider multiple objects, that are enacted into being. In this approach different realities are enacted into being through practices, in complex relationships. Realities sit side by side but are not contained together.

Ontology-in-practice comes with objects that do not so much cohere but assemble

(Mol, 2002: 150)

Law and Lien in their study of salmon fishing argue that empirical epistemology that looks at the ways knowledge is shaped, either theoretical or practical, assumes that there is a stable object out there beyond human control, in this case a salmon. It may be seen from different perspectives but there is ‘a salmon-reality: something outside practice for that practice to get to grips with’ (Law and Lien, 2010: 2). They propose an alternative empirical ontology where realities are enacted in relations, so the emphasis changes to the effects of practice that constitute the realities of the salmon.

The practices may be different but they are not totally separate, they interfere and overlap with each other.

For Law, what is made real, whether that is a statement, a disease, or technical object is always in relationship to what is absent, absence helps to constitute presence. He defines two types of absence; manifest absence, which is recognised, and otherness, which is enacted as irrelevant or impossible and therefore disappears e.g. the organisation of health care. If the focus is on practice there will always be multiplicity, choices will be made; Law (2004) prefers to talk about method assemblage that is about the crafting of boundaries between presence and absence.

In post-structuralism presence by itself is impossible: presence necessitates absence. In research practice this suggests that some things (for instance research findings and texts) are present but at the same time other things are being rendered absent. But what? The answer is: two kinds of things. One: whatever we are studying and describing, our object of research. And two, other absences that are hidden, indeed repressed. Othered.

(Law, 2006: 3 emphasis in original)

An inscription device is a system such as an apparatus that changes a material into a figure or diagram. It is understood to have a direct relationship to the matter represented, and so the process involved is bracketed out (Latour and Woolgar, 1986). Medical textbooks make visible a set of aetiological, physiological and anatomical relations and effects, using the inscription devices of paragraphs, figures, drawings and references. The realities are created and the process of constructing them is concealed. The social only appears in science when mistakes are made, for example people are blamed for something going wrong rather than the method (Latour and Woolgar, 1986).

Fractionality is

a metaphor for expressing the idea that objects, subjects and realities.....are more than one and less than many

(Law, 2004: 160).

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Mol (2002) calls this multiplicity. A number of strategies may be employed to produce singularity when fractitionality occurs. These relate the different realities to each other and include the creation of a single smooth narrative to account for the variety, establishing hierarchies and rationalisation. What Law describes as non-perspectival strategies, include keeping incompatible realities apart in mutually exclusive sites, either in space, time or both, or they may be added together to create a different object. Mol (Berg and Mol, 1998b, Mol, 2002) lists similar options available in what she would call multiplicity of realities. These include mapping different realities onto each other to form virtual objects, privileging one object and finding reasons for, or glossing over differences, using a third measure to arbitrate, or focussing on practicalities. She argues that 'medicine is not a coherent whole' (Berg and Mol, 1998b: 3) and if practices do hang together it is a social construction.

3.7 The body multiple

My starting point is clinical practice, and a theory that best describes the complexities of medical practice to me is Annemarie Mol's 'the body multiple' (Mol, 2002). It reflects the hegemony of health care practice, rather than assuming that all practice is standardized. In a variety of disciplines, medical discourses are seen as objectifying and oppressive to patients, this opposition to biomedicine can mean that bodies in social theory are only considered as a social issue (Pols, 2011).

Mol uses the term 'the body multiple' as a framework for her ethnography of atherosclerosis, which she describes as more than one, but less than many. She is interested in how a disease is enacted in various practices, rather than from different perspectives. The use of 'perspectives' suggests that the number of people multiply but that the disease entity is singular. Mol argues that the disease entity varies to some extent in each clinical encounter; it is enacted with the co-operation of both patient and clinician. Despite some of the recent changes that were discussed in the previous chapter, the use of the term disease is normally left to medicine, while social science concerns itself with illness. I am a nurse, and have been steeped in medical terminology, but I also have a background in social sciences and have found

Mol's approach to be useful in looking at the practice of hallucinations by mental health professionals, people with dementia and carers.

In *The body multiple*, Mol (2002) studied a disease, atherosclerosis, in a single hospital but her framework has been used in wider contexts. In a study of obesity, Throsby (2011) examined enactments of obesity both inside and outside medical contexts. My study looked at enactments of hallucinations in dementia within a community mental health context that included enactments of people with hallucinations and dementia, their carers and nurses.

Mol tells the story of multiple enactments of atherosclerosis

The word 'is' used here is a localized term. Ontology in medical practice is bound to a specific site and situation

(Mol, 2002: 55)

The enactment of a disease differs from a study of a disease where an object of knowledge is the focal point of different perceptions. A singular knowable object called hallucinations in dementia would probably be a definition of a disjuncture with consensus reality. The body multiple refutes the idea that a disease is a single object. In Mol's study, atherosclerosis is enacted in different sites such as a pathology laboratory, and between a clinician and a patient. In clinical settings and outside the medical domain, a multiplicity of hallucinations is enacted.

Like Law, Mol contends that talking about perspectives suggests a pre-existing object that can be known, rather than a disease enacted through encounters in various practices and sites

objects come into being-and disappear-with the practices in which they are manipulated . And since the object of manipulation tends to differ from one practice to another, reality multiplies

(Mol, 2002: 5).

I find this idea more helpful than the multiple perspectives of different realities as it offers a better explanation of the nature of hallucinations in dementia. Realities are

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not given and stable, but are continual enactments that may be the same or slightly different (Moser, 2008). It may be tempting to describe a hallucination as a loss of contact with reality, but as a clinician I have often experienced some common reality with people with hallucinations. In the body multiple Mol demonstrates how a disease, atherosclerosis, which does not initially appear to contest common-sense reality is not singular. How then can dementia in which even Alzheimer's disease is enacted differently in the laboratory and the clinic where 'the biomedical version is not necessarily sovereign' (Moser, 2008: 103) be a singular disease?

there are different and changing versions of Alzheimer's disease, there are *gradients* of definiteness and realness, and (that) these realities co-exist

(Moser, 2008: 104 italics in original)

The nun study is a longitudinal research study of an order of Catholic nuns that examined ageing and Alzheimer's disease. It illustrates some non-coherence in pathological understanding of Alzheimer's disease. A number of nuns presented no clinical signs of Alzheimer's disease in life but autopsies showed plaques and tangles and vice versa (Snowdon, 2001). Although the reality of Alzheimer's disease in the laboratory may be in neurological changes, Alzheimer's disease elsewhere can be very different. Dementia is also re-enacted outside the clinical environment, as something that robs people of their selves, reducing them to empty shells, and as a drain on the health and social care resources of the country. People with dementia are challenging this view by writing blogs, speaking at conferences and contributing to political debate about strategy (Swaffer, 2013, Scottish Dementia Working Group, 2013, DASNI, 2013, European Working Group, 2013).

Mol and Law both move the debate from epistemology to ontology. 'The shift is from epistemology (where what is known depends on perspective) to ontology (what is known is also being *made* differently)' (Law and Urry, 2004: 397). Their thinking challenges three dualisms of human v non-human, knowing subject v passive object and social v nature (Law 2004). Objects are usually assumed to be static until caused to change. Disease changes from an object within the body to different ontologies of medical knowledge that are enacted in different sites within the hospital.

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knowledge is no longer treated primarily as referential, as a set of statements about reality, but as a practice that interferes with other practices. It therefore participates in reality

(Mol, 2002: 153)

Variables are not stable in the body multiple but they change from one site to another. Mol argues there are ‘interferences’ between enactments.

According to Mol coordination, distribution and inclusion are the three main ways in which different enactments of a disease hold together. If a disease is no longer a single object but becomes many objects in the sites in which it is enacted, neither does it become fragmented because somehow all these objects hang together and become less rather than many.

Despite their multiplicity, they do cohere making more than one and less than many. These realities can be co-ordinated in a number of ways so that differences are levelled out in order to form a single disease. They include addition, as in addition of test results with a hierarchy established in the case of conflict and calibration where practices are made equivalent.

I am aware that despite my use of the term hallucinations they have appeared differently in diverse people I have known living with dementia. Sometimes they change within the same person so that I have been unclear whether this is a hallucination, a misperception or a ‘false belief’

the connections are slippery: they elude one’s cognitive grasp, and the illusion of meaningfulness is like that found in a blurred or shifting puzzle picture the content of which seems to change as you try to define it or get it into focus.

(Gillett, 2004: 23)

It is a term I may dispute with people who do not work within mental health, but I am fairly sure that it is a term that my ex-colleagues and I would use as short hand and would have similar understandings. We would ‘*talk* about a single object’ (Law, 2004: 50). Mol describes the use of such a terms as a co-ordinating mechanism that ‘bridges the boundaries between the sites over which the disease is situated’ (Mol,

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2002: 113). She uses the spatial metaphor of distribution because the disease is enacted differently in different sites. Incompatible objects may be enacted but a shared ontology is not needed for medical treatment. Differences are not just about disagreements between individuals, but can be about an individual altering their frame of reference in different sites and situations. Mol does not advocate homogenization, nor is she suggesting pluralist disintegration, but the necessity to examine how differences are handled in various sites and situations. There was a point in this research process when I struggled with the notion of such separate realities that I wondered if it would ever be possible to reconcile my reality with someone who hallucinates despite my clinical experience of such possibilities. I turned into the Red Queen in 'Through the looking glass'

Why sometimes I've believed as many as six impossible
things before breakfast

(Carroll, 1993: 193)

Pre supposition of a single object requires work to co-ordinate, in order to reduce controversies. There is general agreement that people should be treated as a whole rather than as a part of the body, but how much of a whole, Mol describes the possibility of ever increasing circles of patient, family, and community. This suggests a model of inclusion and hierarchy but when examining practices the hierarchical relationship disappears. Treatment decisions are not just based on the state of the diseased part of the body, but other factors sit alongside including social factors. Mol points out that this does not necessarily mean that they are done well. Objects assemble rather than cohering as part of a stable object.

I find Mol's description of the tensions and doubts that exist in clinical medicine resonates with my experience and a useful concept to hold on to as I think about the data that is constructed within my study. This idea of tensions and doubts does not mean that there is 'permanent chaos', however, as 'tensions are tamed' (p181) and realities are co-ordinated through addition, translation, distribution and inclusion.

For my study all this discussion of slippery boundaries and body multiple means that I am not studying a single object, but a shifting dynamic that requires a loose

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approach to method. I am not however assuming that the people I interviewed have different perspectives of the same object, but am assuming that multiple objects are enacted in practice, and there is something that connects all our multiplicities.

Mol's body multiple shifts the realities of disease onto enactments in practice. Within the mental health practice from which this study originated, an integral component of that practice is care. Care and ethics are also situated in practice, and care is theorised in the next two sections, in Mol's logic of care, and in ethics of care.

3.7.1 Logic of Care

Mol addresses the current rhetoric of choice in healthcare in her book 'The logic of care' (2008). In the previous chapter I discussed the competing political agendas of evidence –based medicine and public participation, Mol takes some of these considerations in a different direction. She makes a powerful argument, contrasting a logic of choice with a logic of care. Her argument is not that professional knowledge should dominate, and professionals should provide care to passive patients but that care is shaped in everyday practice in site specific situations. I believe with Habers et al (2002) that 'good' care values long term relationships rather than one off incidents, especially in dementia care. My clinical practice did not fit into the language of choice as much as the language of living well with a disease within relationships. People do not choose to live with dementia, if they were offered the choice they would choose to live without it. Kate Swaffer (Swaffer, 2013) writes in her blog post about living with dementia and losing control

I have to 'adapt to' my new and evolving limitations. I have not choice. I have lost control. It is better to accept these facts than rail against them for too long

Mol (2008) argues that control of the body is not an option when living with diabetes, but that one needs instead to be attentive to one's body. This is also the situation for many people with dementia, they may lose control of aspects of their cognitive processing, and it is not a private matter, but involves other people within relationships.

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Favoring care not choice risks the criticism that what is being advocated is the patronization of people with disabilities who are not to be given the same choice as ‘us’ (Barnes, 2012). It may initially seem counterintuitive to reject choice especially in a field where people with dementia have been so thoroughly denied choice in the recent past, but Mol’s contention is that choice and care have different logics. Her illustrations of the arguments made through the lives of real people living with diabetes, situate them squarely in practice. The practices of care are embodied and diverse and

good care (is) persistent tinkering in a world full of complex
ambivalence and shifting tensions

(Mol et al., 2010: 14)

Mol’s claim is that choice is based on the assumption that ‘we’ in the West are all autonomous individuals, as opposed to the ‘other’ who live collectively. This homogeneous view of the ‘other’ has been disputed by post-colonialists and care ethicists amongst others (Saïd, 1978, Spivak, 1988, Tronto, 1993). Post-colonialists criticize this view as a caricature that reinforces the depiction of Western man as modern, rational and civilized as opposed to the Other, which is romanticized as irrational, weak and feminine (Saïd, 1978). The argument of the care ethicists is discussed in the next section. The idea of the individual continues to inform the ideal of choice.

The logic of choice can be associated with the market, where patients become customers, weighing up the goods presented by a clinician, who provides information, enabling the patient to make a one off choice. They make one choice and then have to live with this choice, meaning that if it is wrong they will be blamed. It ignores the ongoing activity of the person with the disease. The logic of care, however, recognizes that care is a process where people who live in relationships, and clinicians work together to improve the practicalities of living with a disease, which may be erratic. This reflects my practice as a nurse and I hope I continued it into my research relationships. My study explored how people lived with dementia and hallucinations.

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The practice of care is non-coherent, it may involve different priorities at different times, in clinical practice the priority may be about biomedicine at one time, at another it may be about spending time with people or relatives

care is about finding the least worst ways of putting different and non-coherent versions of the good together. It is about holding the goods together for the moment in the full knowledge: that cut across one another: that they are in tension: and that they do not fit

(Law et al., 2013: 15 Italics in original)

Living with a disease in this way allows for flexibility, if something does not work the patient is not blamed, but perhaps another approach can be tried. There are professional and ethical arguments for good care but both need to be integrated together within daily practice (Habers et al., 2002).

Professionals bring a knowledge that should be used in dialogue with the particular knowledge of the person living with the condition (Barnes, 2012). Responsiveness is an integral part of ethic of care (Tronto, 1993). It also recognizes the care work being done by patients; there are people with dementia who recognize that they get tired easily and so limit their activities, or who know they may get lost going out so only go on certain routes, or go out with other people.

3.8 Care and ethics

Ethics of care has brought care into the agenda of ethics. People are not seen as autonomous individuals but as living in relationships in specific situations. Care is a contested concept within our society, despite its ubiquity within everyday discourse (Barnes, 2012). Recent debate in the media about care in hospitals illustrates this only too vividly (Guardian, 2013). Concerns about poor care in a hospital in Stafford became a public scandal. Objects of blame for the failings at the hospital have ranged from individual nurses who are unable to care, to government policy that is dismantling the NHS. Despite the recent controversies, understanding of care is fragmented, and various types of care continue to be apportioned different worth within our society (Tronto, 1993).

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An ethic of care approach addresses ethics as situated within a concrete situation rather than as abstract principles (Shakespeare, 2000). Care is ubiquitous throughout the lived experience of life, and has been a major consideration of my clinical work with both people with dementia and carers. Many of the people with whom I worked are living in interdependent situations with others, and no-one can be seen as an individual divorced from their social contexts. It is also an essential element of the ethical framework that I used throughout my research. In the world of clinical practice it is rarely possible to use the straightforward approach of adopting a universal principle, there are always undertows pulling in different directions (Hughes, 2011).

Care-work is perceived as encompassing a narrow range of activities, is gendered and devalued. It is associated with women and traditionally belongs in the private realm (Thomas, 2007, Twigg, 2004). It is viewed as dirty work, involving bodily fluids that rightly belong in private space. The public realm belongs to 'higher aspects' of disembodied, rational and male values (Twigg, 2004). It is however being relocated out with the home with more caring being done by care workers. Alongside a shift in the focus of medicine from cure to care, this has led to caring becoming more of a social and political issue (Sevenhuijsen, 2003). Older people are expected to live well into old age, they are aware of the risks that arise from being seen as dependent (Lloyd, 2004, Ward and Gahagan, 2010) and people with dementia in particular are described as part of a global epidemic that will impose a significant socioeconomic burden on society.

Originating in political activism, the disability movement grew in response to a perceived need by people with disabilities to address the social oppression that resulted from being marked as different. The advocacy movements in mental health and dementia are now joining this debate but not everyone with dementia is able to embrace the right to choice in this political way. As Barnes (2012) points out there may be a danger that we create a different boundary around those of us who are valued as autonomous individuals.

The disability movement offers a different perspective on caring, claiming that care results in other people trying to dominate their lives. They would contest the attribution of dependence, which is a devalued status, but not deny support needs (Thomas, 2007). Tom Shakespeare (2000) advocates the use of the term 'help' rather than care because of its contested and value-laden associations. Help removes the emotional component of care and although I understand the thinking behind this argument, I am not sure how useful it is to try to remove the emotional and relational aspects of a care relationship. An ethic of care framework replaces the potential for paternalism with the need for responsiveness and trust within care (Tronto, 1993, Sevenhuijsen, 2003).

Care can also be associated with emotions that are gendered, but it is difficult to imagine any interaction without an affective component. Primacy is given to relationships within psychotherapy (Bondi, 2008) and I would also contend within mental health nursing. My study uses a process consent method (Dewing, 2007), discussed in the next chapter in which the relationship between the researcher and participants is integral. Dementia care has increasingly recognised the importance of the social context for the experience of the person living with dementia (Kitwood, 1997, Sabat, 2001).

The goals of healthcare used to be the attainment of health but with the changing nature of prevalent diseases it is now more likely to be care. Care has been complicated by the agenda of the lived experience of the disease and shifting balance of much of the work of healthcare to chronic disease management (Mol, 2006). People may be active for longer or may need social care as well as medical care (Sevenhuijsen, 2003). There is currently no cure for dementia, but there has been a change in practice towards giving people an earlier diagnosis. A division between cure and care is artificial, in practice they intersect. Medical interventions or good care may well be devised to enable people to live the best way possible for them, with their condition, whether that be diabetes or dementia (Mol, 2008). Barnes (2012) points out that not all care is good care, people get it wrong, both paid care workers and friends and family. This does not mean that the use of the term should be discontinued, although perhaps that we should be more evaluative in our use of

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the term. Mol (2008) agrees that centring on care does not mean that all practice is good, but does not believe it will necessarily improve by advocating a policy of patient choice.

3.8.1 **Care and autonomy**

Both logic of care and ethics of care challenge the prevalent discourse of autonomy and individuality (Mol, 2008, Barnes, 2012). Harrigan & Gillett (2009) highlight that the notion of autonomy is based in the modernist view of individualism, which disadvantages those who are impaired. They cite the view of Kitwood who thought individualism was valued at the expense of individuality and argue that there is a need to value the more situated, relational self, a 'being-in-the-midst-of-others' p52.

Debates about autonomy go to the heart of the question of what is a person. As discussed in the previous chapter, this can result in the devaluation of the person with dementia and their re-ordering as non-persons within our society.

Care offers a counterbalance to a perspective that emphasises the cognitive and rational dimension of what it is to be human

(Barnes, 2012: 12)

It offers a different perspective to that of the 'hypercognitive society' described by Stephen Post (2000).

Challenges to autonomy also come from a variety of cultural perspectives (Hulko and Stern, 2009, Tsai, 2009). Different cultures have different views of how a person is constituted, and also how decisions should be made, suggesting that autonomy and decision-making are socially constructed. Feminist perspectives have similarly questioned the idea that autonomy should be prized more highly than relational values in achieving well-being (Gilligan, 1982).

Autonomy neglects social and interrelational contexts, in which decisions are made in ordinary life, and disadvantages those with dementia who may require help to achieve autonomy (O'Connor et al., 2009, Jaworska, 1999). The Nuffield Council on Bioethics (2009) report on ethical issues in dementia points out that people do not

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make decisions in isolation and recommends that joint decision making, where appropriate, should be an approach incorporated into the codes of practice of the Adults with Incapacity (Scotland) Act and the English Mental Capacity Act.

3.8.2 Ethics of care

Following its beginnings in feminist psychology, ethics of care has extended into political philosophy, care is not just seen as a personal but also as a political concern (Brown et al., 1989, Gilligan, 1982, Gilligan, 1998, Barnes, 2012). Ethics of care informs both my thinking and the practice of my research. Ethics of care originates in the psychological theories of moral development in the work of Carol Gilligan (1982). Gilligan concluded that moral reasoning is gendered, reaching a different conclusion from her colleague Kohlberg who described the development of a universal justice ethic. Gilligan argued that women speak ‘in a different voice’. According to her study, women’s voices revealed judgements that were in general based on contextual reasoning rather than considering some abstract dilemma. Although Gilligan has been criticised for being essentialist, her work has been hugely influential, and has been widely cited in academic literature that has considered feminist ethical ideas (Tronto, 1993).

Feminist care ethicists and disability rights campaigners have both argued against the false dichotomy between care and justice (Sevenhuijsen, 2003, Tronto, 1993, Barnes, 2012, Shakespeare, 2000). Shakespeare calls for a dialectic between the two with a commitment to the re-situating of welfare into an ethics agenda that would allow for justice and compassion, and rights and care.

The extension of ethics of care into the philosophical and political arena by Tronto (1993) in her seminal book ‘Moral Boundaries’ has broadened the debate, from a gendered issue, into the moral dimensions of care and caring relationships as practice. Tronto’s definition of care which she developed with Berenice Fisher is wide ranging

On the most general level, we suggest that caring be viewed as a *species activity that includes everything that we do to maintain, continue, and repair our ‘world’ so that we can*

live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web.

(Tronto, 1993: 103. Italics in original)

Ethics of care has provided a framework to examine care in policy (Sevenhuijsen, 2003), a variety of caring relationships and settings (Barnes, 2012) including dementia care (Brannelly, 2006, Brannelly, 2011), and research practice (Ward and Gahagan, 2010).

Ethics of care contests the concepts of the person as an autonomous individual with a desire for self-determination, that as I have argued has implications for the way that vulnerable people such as people with dementia are valued in society.

Care ethics offers a relational, interdependent view of human beings. We are all relational beings, but care needs may become more overt when we are vulnerable.

Care offers a counterbalance to a perspective that emphasises the cognitive and rational dimension of what it is to be human

(Barnes, 2012: 14)

Our need for care in everyday life is hidden in an agenda that values autonomy, and associates the expression of a need for care with being a less than whole person. Being identified as in need of care, is viewed as being dependent, and therefore of less worth (Barnes, 2012).

Tronto (1993) describes four phases of care with the moral elements or values involved.

Caring about and **Attentiveness** recognises that there is a need for care. In Tronto's opinion this requires us to attend to the need for care more widely than just amongst the people we know. It includes a societal approach, and at the same time recognises a need for self-care. As Barnes (2012) argues a belief that people are autonomous individuals makes attentiveness less likely.

Situating knowledge

Taking care of and **Responsibility** comprise willingness and a capacity to act. She distinguishes responsibility from formal duties or obligations. It involves seeing a need and acting on it, providing a more flexible approach than prescribing the obligations to care within specific relationships.

Care giving and **Competence** require resources, including knowledge, to ensure that care needs are met. Care is competent if it is good care, Tronto does not think bad care should be described as care.

Care receiving and **Responsiveness** highlights the interaction involved in care. The meaning to the care receiver, of the care given, is vital to care. It underlines vulnerabilities and potentiality for abuse.

Selma Sevenhuijsen (2003) added the further element of trust to Tronto's categories. Trust is bound up with power and responsibility and requires a willingness to be open to the other.

Brannelly (2006, 2011) has used an ethic of care framework to evaluate ethical practice within dementia care. This skilfully illustrates the complexities involved in caring for people with dementia within relationships. Hearing the voice of the person with dementia can be compromised by their disabilities, the systems of care and the prevalent discourse of caregiver burden that leads to the needs of the professional or carer being met before that of the person with dementia. Conflicts can arise within dementia care and good care requires a continuous process of negotiation with all members of the caring network (Barnes and Brannelly, 2008).

3.9 Summary

In this chapter I have considered theoretical approaches towards understanding complexities. I have looked at various ways that boundaries are transgressed, challenging the view that we can achieve a 'view from nowhere'. The work of John Law and Annemarie Mol contest the use of perspectives as an explanation of different realities and instead ground differences within ontology. Realities are enacted in practice, so knowledge is always partial and situated.

Law et al. (2013) remind us to be wary of grand narratives. They argue that there is little permanence within care practice; it can be variable and non-coherent. Good care is about managing uncertainties that are in tension. Multiple realities that may not cohere can still be held together through practice. Care involves ‘tinkering’ (Mol, 2008), acknowledging multiplicity, and managing the tensions that exist within differing knowledges.

Attending to practices means working empirically and I did this through case studies as described in the next chapter. My understanding of hallucinations in dementia is that they are enacted differently in practice by professionals. They never achieve unity but they are somehow connected so they are ‘more than one- but less than many’ (Mol, 2002: 55).

Ethics of care extends the literature on carer burden and situates the person cared for, and the carer, within a symbiotic relationship. It argues that people exist within a network of relationships, and this informed my research design of a triadic case study with a person with dementia, a carer and a mental health professional. Ethics of care recognises the importance of care in relationships rather than losing sight of it, it argues against the individualism (Barnes, 2012) that has devalued people with dementia. I used an ethic of care framework for my data analysis as discussed in the following chapter.

4 Research design

In this chapter I discuss the design of the study from its inception, identification of research issues through the design and process of conducting the research to analysing the data. Law (2004) warns against seeing method as clear and precise when the world it tries to capture is messy. Social research methods have not dealt well with objects that may be transitory, complex and multiple. My journey was not straightforward and I include reflections on the challenges I encountered, both with practicalities and to my self-conception as a nurse and researcher along the way.

4.1 Developing the design

Previous studies of hallucinations in dementia have been epidemiological and large scale clinical trials. They have not included the perspective of the person with dementia. I did not want to study hallucinations but the experience of people with hallucinations; I wanted to explore the particular not the general. It was evident to me from the start that this was going to be a qualitative study. Statistical studies see people as passive in the face of variables (Frank, 2000), I believe that people are situated and relational. My practice has been based on establishing therapeutic relationships with individuals within their networks. I wished to maintain the way I have always worked with people with dementia. As with much qualitative research my design decisions were made at the start but they were affected by the research practice and context (Mason, 2002).

My understanding of hallucinations in dementia was situated in community mental health care. My belief was that hallucinations occurred primarily as a result of changes within the brain, caused by dementia, but that they could be exacerbated by environmental and interpersonal factors. They were often a reason for referral to community mental health teams and these understandings influenced my design. The primary aim of the study was to explore differing realities of hallucinations of people with dementia, their carers and community mental health professionals. A research design links the original questions to be asked with the data to be collected (Yin, 2009). This sounds deceptively easy until the complexity of the subject matter is considered. Jennifer Mason (2011) paints an image of capturing a butterfly that

loses its essence when pinned down in order to enable us to study it. This notion of the ephemeral, which changes when it is captured is akin to Gillett's (2003) description of psychotic phenomena as a slippery concept. The previous chapter discussed elusive objects and non-coherence as understandings of ontology, and also of hallucinations.

I considered using ethnography for my study but the practicalities involved in observation of people who live at home would make it too intrusive. People who hallucinate do not necessarily do so constantly, nor do they experience hallucinations at regular times of the day. I was unable to observe the practices of my participants when they experience hallucinations and so I was reliant on their narratives, they become the ethnographers.

There is a need to find methods that have various vantage points to expand sensory dimensions (Back, 2012). Taking this into account, I used some illustrations alongside interviews from different sources-the person with dementia, their carer and their mental health nurse. The study was designed to elicit in-depth information from people, and in-depth interviews were the main method of collecting data.

4.1.1 Research issues

My research issues emerged, grew and changed focus throughout the data collection.

My initial research questions were

- How do people with dementia describe their experiences of hallucinations?
- What are the understandings of carers and professionals of hallucinations in dementia?
- How are reality disjunctures negotiated in caring relationships?
- How do people with dementia and their carers co-construct identity when disrupted by reality disjunctures?

These could be described as foreshadowed questions. They changed during initial fieldwork and with my reading. My understanding of Mol (2002) and Law (2006,

2004) and the particular data from my participants led to my research issues as follows

- How do hallucinations affect the daily lives of people with dementia?
- Do hallucinations impact on the self identity of people with dementia?
- How do the multiple practices of dementia and hallucinations hang together?

A case study celebrates the particular rather than looking for certainty (Simons, 1996) and is therefore an appropriate methodology for the study of something as uncertain as hallucinations.

4.2 Case study

4.2.1 Introduction

Case study has been used since at least the time of Socrates and has continually been disputed as less valuable than general theoretical knowledge (Flyvbjerg, 2001).

Flyvbjerg (2006) tackles five misunderstandings about case study in his frequently cited article. He counters understandings of case study that refute its validity and reliability as a method. A common argument against case study is that it cannot be used to generalize. Flyvbjerg's response to this is

One can often generalize on the basis of a single case, and the case study may be central to scientific development via generalization as supplement or alternative to other methods. But formal generalization is overvalued as a source of scientific development, whereas "the force of example" is underestimated.

(Flyvbjerg, 2006: 228)

4.2.2 Traditions of case history in psychological medicine

Historically, case studies have been used in diverse disciplines for different purposes, and most people would argue that professional case histories are different from case study research (Simons, 2009). Case histories are familiar to me through medicine and psychotherapy and although not necessarily used for research, they are certainly used for teaching purposes and presentation of new treatment approaches. The

original description of Alzheimer's disease was published as a case study (Maurer et al., 1997). They are still valued in medicine as having scientific value and serve as an adjunct to randomised controlled trials. Case history in medicine, however, normally follows a formalised structure, with an invisible narrator telling the story of the patient in a detached manner (Hornstein, 2012). The role of the doctor as an instrument is ignored resulting in the presentation of the case as 'objective' (Simons, 2009).

Since the time of Freud case studies have been employed in psychotherapy as a way of documenting and disseminating new forms of therapy and developing practice (McLeod, 2010). Radley and Chamberlain (2001) argue that case study should be used in social science research by health psychologists because of their 'dual relationships' as researchers and practitioners. I would contend the same argument applies in nursing research.

Although case studies may differ from case histories, Flyvbjerg (2001) argues that people learn and become expert practitioners through context dependent knowledge. Case presentations are used to re-present the initial presentation of the patient to the doctor. As Hunter goes on to highlight

The case presentation is the fundamental medium of clinical thought and discourse

(Hunter, 1992: 68)

4.2.3 Case study research

There are many definitions of case study research and a variety of methods can be used but its main feature is that a social unit is studied as a whole. The definitions have different emphases: for Stake (1995) the stress is on the singularity of the case and for Yin (2009) it is the real life context, but they are all committed to complexity and contextuality (Simons, 2009, Sabat, 2001). According to Simons

'case study is an in-depth exploration from multiple perspectives of the complexity and uniquenessin a real life context'

(Simons, 2009: 21)

Case study is appropriate when studying phenomena in depth and in context especially where there may be difficulty in differentiating between phenomena and their context (Yin, 2009).

Stake (1995) describes three types of case study, whilst acknowledging that it can be difficult to differentiate

- Intrinsic case where the interest is in the particular case
- Instrumental case where insight into the subject of interest is achieved by studying a particular case
- Collective case study in which several cases are chosen to study the instrumental

I chose to study the experience of hallucinations in collective cases. The cases were also triadic, involving a person with dementia, carer and mental health nurse. A psychotherapy case consists of an episode in which a person or family group receive help from a therapist (McLeod, 2010). I am borrowing the triad from a therapy case although am not studying the therapeutic intervention directly. Community mental health nurses work with people within family units and this informs my choice of triad.

The outcome of a case study is a case description and descriptions of each of my triadic cases are presented in the following three chapters.

Case study and narrative are often linked and in the following section I discuss my decision to use a narrative approach within my case studies.

4.3 Narrative

‘Case studies often contain a substantial element of narrative’ (Flyvbjerg, 2001 p84).

Case studies produce narrative knowledge, stories are told about the everyday within cases (McLeod, 2010). Medicine is full of stories that are told daily, stories are told by patients to health professionals, doctors tell stories about patients within formal

settings such as case conferences or informal settings, talking amongst themselves (Atkinson, 1981, Hunter, 1992).

I am interested in their experience of hallucinations, but recognise that this occurs within the context of a lifetime of experience that may well affect the hallucinations. I hope that the narratives of the people involved in the study also tell something of groups of people with dementia who hallucinate, their impact within relationships with others, and the effects this may have on their identity within the wider society. I have always been sure that I wanted to use narrative in some way for this research, but I started from a naive notion of narrative. One of the most rewarding aspects of my work had been listening to the stories people told me, and I felt that this was an important aspect of both establishing, and maintaining a relationship. Listening to the individual stories that patients tell has long been an important feature of medicine and comparing those individual stories to others, assists doctors in identifying the correct diagnosis and treatment (Stake, 1995, Frank, 2000). This does not necessarily mean that the patient feels they have been listened to. Perhaps the story told by the physician is not the one that they wish to have told, and it is certainly not the only story that can be told. Medical narratives are, however, part of clinical life with more kudos gained for those who are able to tell a story well, and have an unusual story to tell (Atkinson, 1997, Atkinson, 1981).

I hope to avoid the danger identified by Atkinson (1997) of valorising the lifeworld experience of the person with dementia and demonising the medical by using a triadic case study approach. Using the theoretical approach of Mol (2002) should also contribute to this. If reality is seen as enacted in practice then it is firmly situated. As she shows in her description of some of the encounters she witnessed, the atherosclerosis may be enacted in the doctor's surgery as pain in the limbs, which results in a person having difficulty in shopping.

I was fascinated by the life experiences of the older people with whom I worked, but realised it would not be enough to merely tell their story, again. Atkinson (1997) warns against this as he points out there is a need to analyse the data. The omnipresence of narrative throughout our culture, which is often associated with the

cult of the individual (Riessman, 2008), can lead to an assumption that narrative speaks for itself. We can only know what is narrated and make our own interpretation of it, rather than knowing any ‘true authentic self’ through narrative. Narratives are, however, interpreted through an understanding of broader social structures (Doucet and Mauthner, 2008).

Narrative research has become increasingly popular in social research over the past few decades, but as with so many conceptualizations in social research, the use of the term ‘narrative’ is diverse; perhaps there are many enactments of it. It is not the sole provenance of social research; it is used in the humanities and is widespread in all public life. The term narrative is not reserved solely for interview data, narrative research is conducted using official and personal documents, such as diaries and letters, as well as visual images (Riessman, 2008, Quinn et al., 2012). Narrative is often used synonymously with story, as Frank (2000 : 354) points out, it sounds strange to say I told a narrative, ‘people do not tell narratives, they tell stories’.

Narratives are everywhere, they are how we make sense of the world, how we tell of our experiences, and how we tell of ourselves; we live in a ‘storied world’ (Riessman, 2008). Stories are ubiquitous and are the fundamental way we communicate with each other. Law (2004) would say that narratives are how we depict realities, and there is no single account. When we are unable to make sense of the stories people with dementia tell us, this may contribute to the judgement that they are losing their identity. The only reality we are recognising is-that of a damaged brain.

Coinciding with the upsurge in illness narratives (Frank, 2000), there has been a rise in the number of narrative accounts of life stories, in studies of older people. There have been a small quantity of narrative accounts of people with dementia (Sabat, 2001, Crisp, 1995, McLean, 2006).

Alongside the narrative turn, there has been an interest in the concept of the ‘narrated subject’ (Doucet and Mauthner, 2008). Somers (1994) argues that we come to know ourselves through narrative. She contends that narrative should no longer be seen as

a representation but as something that is constitutive. Narratives are rooted in time and space, and describe who we are and what we do. Alongside this understanding is the argument that narrated subjects are relational (Stanley, 1993). The previous chapter discussed an ethic of care approach and this relational view of narrated subjects reiterates the understanding that no one is an isolated self.

Postmodernism has challenged and shattered meta-narratives, including a belief in the centrality of a core self (Gubrium and Holstein, 1994). Despite this shift from the idea of a coherent unchanging self, towards a narrative self (Holloway and Freshwater, 2007, Holstein and Gubrium, 2000), narratives of people with dementia may be treated with more suspicion. They can be viewed as less valid because of a perceived lack of coherence; they can clash with other scripts about dementia in which the person has lost touch with reality (McLean, 2006).

I will now review my research questions in the light of the discussion of narrative

4.3.1 Research questions revisited

Accessing the experiences of others is notoriously difficult (Kendall & Scott), before adding an uncanny experience such as hallucinating. The research was designed to address a gap in the literature, namely exploring the impact of hallucinations in dementia. My approach to exploring these research questions was informed by both STS literature (Law, 2006, Law, 2004, Law and Mol, 2002, Mol, 2002, Mol, 2008), as discussed in the previous chapter, and narrative inquiry (Riessman, 2008, Hydén and Brockmeier, 2008). There is ambiguity in the way that narrative is used in social science research (Polkinghorne, 1995). It is used, often interchangeably with story, to describe the data that emerges from research, or it can be used to describe the form that research takes, and how it relates to sociocultural contexts. I use it in both ways in this thesis, viewing the data from unstructured interviews, and Figure 5, as narrative, and also using a narrative method of data analysis.

The study aimed to explore different realities of hallucinations in dementia. I use ‘realities’ not to suggest an objective, rational truth but as the flexible and multiple enactment of reality discussed in Section 3.6. In Chapter 2 I discussed the multiple

narratives of dementia, some encompass the same ground, but there can be differences between specific contexts. Hallucinations are internal experiences that cannot be observed but it is possible to listen to the narratives that emerge from these experiences. I used a narrative approach to data analysis that enhanced my ability to listen to multiple voices (Section 4.10). Narratives of people with dementia, carers and professionals were all elicited in this study but those of people with dementia were privileged. Different realities are constructed that interact and interfere with each other.

Bruner (1987) in his conceptualisation of ‘life as narrative’ argues that narrative knowledge differs from paradigmatic knowledge. Both ways of knowing construct reality differently. Paradigmatic knowledge traditionally categorises, moving from the particular to the general and the abstract whereas narrative knowledge attends to the particular (McLeod, 2010, Polkinghorne, 1995). Care is also practised at the level of the specific, and my exploration of hallucinations in dementia is based in an ethic of care approach that conceptualises care as occurring within relationships.

My first research question addresses how the daily lives of people are affected by hallucinations.

‘A storied narrative is the linguistic form that preserves the complexity of human action with its interrelationship of temporal sequence...and changing interpersonal and environmental contexts’

(Polkinghorne, 1995: p7)

Narratives are an elemental way that we make meaning, life is storied (Flyvbjerg, 2001, Somers, 1994, Robertson, 2013). This includes making sense of illness (Frank, 1997, Bury, 2005, Bury, 1982, Bury, 2001), as discussed in Section 2.5 and also within clinical practice (Atkinson, 1981, Hunter, 1992). Within the context of my first question, I anticipated storied accounts to emerge from my research interviews, as narrative appears to be the only method humans have to describe lived time. We continuously interpret our experiences using narrative knowledge (Bruner, 1987).

My concern with identity is premised on an assumption of narrative identity (Somers, 1994). Narrative identity is developed in interaction with a concept of self, and that of others (Steeman et al., 2011). This understanding resonates with the self, conceptualised by Sabat (2002, 2001, Sabat and Harré, 1994), and that implicit in a voice centred relational analysis (Section 4.10). This provided an analytic structure around the way people talked of themselves, their relationships and sociocultural contexts.

My final question arose from my understandings of Mol (2002) and the idea of ‘The Body Multiple’ and care practices that hold non coherence together (Law et al., 2013).

4.4 Ethical context

In this section I will discuss the ethical procedures required for the study and also the way that ethics was produced within my research relationships. Ethics of care was discussed in the previous chapter and informed my ethical framework for this study. It highlights the situated nature of ethics, which happens through relationships. This includes both the conduct of the researcher and reciprocity. Ethics is part of the whole research process; I do not believe that ethics should be a one off procedure and I strived to be an ethical researcher throughout the study. My participants were recruited through the NHS, which meant there were certain institutional ethical procedures to which I had to adhere. The procedure for ethical applications within the NHS are comprehensive, covering any conceivable research study and tend to be orientated towards medical quantitative studies.

4.4.1 Ethical and managerial approval

This study recruited people who lived in their own homes but recruitment was via community mental health teams and also involved interviewing NHS staff, meaning that approval had to be sought through the NHS ethical procedure. This was a two pronged process involving application to both the NHS ethical committee, and the local NHS Research and Development department.

People with dementia may be considered vulnerable, and issues of capacity and consent in research are complex. Initial capacity to consent was part of my inclusion criteria, but I did not want to automatically exclude participants if this changed during the study. This required that I sought approval from the regional ethics committee that considers research involving people who do not have capacity.

Ethical approval was granted in January 2011 and NHS Research and Development approval in April 2011. I then had to get approval from managers to recruit from their sites. This proved more elusive as my applications were made at a time of structural change to the service. I contacted five managers by letter but received replies only after follow-up telephone calls or emails. Responses varied in the procedures they then requested, from wanting me to contact local nurse managers to wanting me to contact consultant psychiatrists for their permission. All this proved more protracted than I had anticipated and so it took until November 2011 until I managed to meet all the teams.

4.4.2 Ethical procedures

As previously stated I recruited only people who had capacity to consent to take part in research. The Adults with Incapacity (Scotland) Act provides a legal framework regarding capacity in Scotland (Scottish Government, 2002). Within the Act one either has or does not have capacity. Thinking has shifted from a focus on the global assessment of capacity to a situation specific assessment, as recognised in the Adults with Incapacity (Scotland) Act. O'Connor and Donnelly (2009) argue that there is a lack of agreement as to what this would look like in practice. The guidelines for practice from The Mental Welfare Commission (2006) point out that capacity may fluctuate and that practitioners need to take into account emotional and experiential factors when patients make decisions.

I relied on the gatekeepers, members of the community mental health teams to decide whether people had capacity to consent. I developed a procedure to follow, should this change during the study (Appendix 1) as I did not want to automatically exclude them. None of my participants did lose capacity during the study period.

Although recent legislation has clarified legal issues, the ethical issues relating to care and research with people with dementia remain complex. The agenda of personhood and person-centred care, and an increase in social research that focuses on the experience of the person with dementia rather than the perspective of carers has resulted in new ethical challenges for both practitioners and researchers (Bartlett and Martin, 2002).

4.4.3 **Consent**

Consent is related to capacity and competency but these are not synonymous (O'Connor and Purves, 2009). Informed consent is traditionally associated with

- Understanding the information given about treatment or research
- Appreciating the relevance of the information for one's own situation
- Evidencing the ability to make a choice
- Communicating that choice

The guidelines from The Mental Welfare Commission address the problem with definitions within the legislation as being one of memory and is of the view that

The person should be able to retain information long enough to make a decision. In addition, we believe he/she must

- Remember the decision: and/or
- Make the same decision consistently given the same information: and/or
- Agree with a record of that decision when presented with a record of it

(Mental Welfare Commission for Scotland, 2006: 9)

Informed consent can pose problems within medicine as a whole, not just dementia and mental health. According to O'Neill (2003) issues of informed consent have been more widely debated in medicine over the past twenty-five years, which has been partially attributed to fear of litigation. He agrees with some sociologists who have described practice for informed consent as a ritual that lacks consensus.

O'Neill identifies the difficulties for medicine as

- Competence- medicine is more likely to come across issues of competence than other areas
- These can be permanent or temporary as in the situation of someone who is unconscious
- Public health situations- where informed consent from the whole population is impossible.
- Treatment decisions- are often made on the basis of information about third parties who have not given consent, such as family history

The informed consent process may cause difficulties for people with dementia in understanding, preference and information procedures (Vass et al., 2003). Holt et al (2008) describe difficulties in recruiting people with delirium to studies because of the acute onset and fluctuating capacity. Capacity may well fluctuate in people with dementia and this can be an issue especially for people who hallucinate.

Informed consent as a one off process can pose difficulties for ethnographic research where there is an expectation that the nature of research will develop within a relationship and thick descriptions are sought. This leads to questions as to what exactly the participant is agreeing to at the start of the research process (Parker, 2007). There have also been arguments that informed consent is based on the idea of individual autonomy, which as I discussed in the previous chapter can disadvantage people with dementia (O'Connor and Purves, 2009, Harrigan and Gillett, 2009).

Murphy & Dingwall (2007) discuss some of the issues for informed consent and ethnographic research. A discrete episode of informed consent is more appropriate to clinical trials or experiments but qualitative researchers can spend long periods in the field. Consent is likely to be continuously negotiated and possibly extended as the relationship develops, based on trust. Research design and focus within ethnographic research may be flexible so that only partial information can be given at the start of the study. I tried to address some of these issues by using the consent flowchart and by adopting process consent throughout the study.

4.4.3.1 **Process consent**

It is important that issues of consent are seen as part of a process, rather than a discrete one off event, especially within qualitative research where there is an on-going relationship between researcher and interviewee (Bartlett and Martin, 2002, Dewing, 2002). Process consent fitted with my ethic of care framework and I used it throughout the study.

Process consent has been recommended as a good principle to be adopted in psychiatric nursing practice as well as qualitative research, including research with people with dementia. It changes the focus from the ritual of informed consent to consent within relationships. This means monitoring consent throughout the research relationship (Usher and Arthur, 1998, Dewing, 2002, Keady et al., 2009). Jan Dewing (2002, 2007) identifies five elements of consent within the research relationship

- Background and preparation
- Establish basis for consent
- Initial consent
- On-going consent monitoring
- Feedback and support

Consent was continuously negotiated throughout this study. Potential participants were initially approached by members of the mental health teams who asked them for permission to give me their contact details. I contacted them by the method advised by the professional. I then spent time with potential participants going over the study information sheet and the consent form (Appendices 2&4). I was flexible in my approach to this, allowing the person with dementia to decide whether they wanted to do this alone or with someone else present. The formal process requested by the Ethics Committee required written information sheets and consent forms. Although I tried to make them as clear and simple as possible, I also needed to follow this up verbally, as one of my participants in particular had difficulty in

reading a lot of material. Allowing them time to complete the forms by leaving them with participants to consider also meant they could ask for assistance from others.

4.4.3.2 Consent for carers

Some of the consent issues for carers were similar to those for people with dementia. Within my research design I only wanted to interview them once, but I left the decision to the person with dementia whether they wanted the carer present during all interviews. One of my participants was interviewed with his carer on each occasion; the other two relatives were interviewed once. It was important that I try as much as possible to ensure that neither party were pressurising the other into consent.

The Ethics Committee required that I had a different consent form for carers (Appendix 5).

4.4.3.3 Consent for mental health professionals

On the face of it consent from professionals seems more straightforward. They were also to act as gatekeepers for my study so the Information Sheets were slightly different (Appendices 3 & 6). On reflection, perhaps I should have had separate sheets for their participation in the study and for their role in recruitment. Initially I decided to recruit professionals for focus groups and finally I interviewed the individual nurses attached to my participants with dementia.

4.5 Negotiating access and recruitment

Setting up the study proved to be a more lengthy process than I had anticipated for a number of reasons, some of which were discussed earlier in Section 4.4.1.

Recruitment was slow and I ended up recruiting individual mental health nurses rather than groups to the study. This was a decision which was to inform my cases to better effect than the original plan to use focus groups.

The nature of the participants I sought to recruit is a reflection of my understanding of hallucinations as a cause for concern that should be addressed by mental health services.

I knew that there would be a limited number of people who were eligible. For this reason I made the decision to approach all the community mental health teams within a selected NHS regional board. As previously stated, it took some time to secure approval from the managers and to succeed in speaking to each of the teams.

4.5.1 Context

Participants were recruited from within a single Health Board. The area was a mixture of large city with geographical mental health teams and day services, and mixed rural and suburban sites out with the city. The teams consisted predominantly of mental health nurses but some also had occupational therapists. Consultant psychiatrists were attached to each of the teams but they also worked in other services as well as the community teams.

4.5.2 Gatekeepers

Recruitment into studies is of central importance to the success of the study and can be challenging in healthcare because of workload commitments of health workers and also lack of interest in research, or research fatigue (Broyles et al., 2011).

I was reliant on mental health teams as gatekeepers for my study. The fact that I knew many of these professionals can be seen as a help or hindrance in a study design. My relationships with them may have given them confidence in my attitude and skills with people with dementia, but may also have made them feel more obligated to help. My knowledge of their work pressure may have resulted in me not wishing to add to it and so not pushing them to find me recruits.

The initial responses from team members were encouraging, they were interested in the study but few could immediately think of anyone who might fit my criteria, I was aware that these teams were about to undergo structural changes and were also under pressure which impacted on my ability to recruit easily.

I realize that much of the recruitment process can be opportunistic, being visible. I am not sure if I can achieve this with so many possible sites. It is not the same as being able to spend time in a residential or hospital setting, as team

members come into their offices at different times of the day and this is to write notes or to use the telephone.

Extract from Field work diary

In the end two of my three participants were recruited via the same team. I had been in their office before doing an interview and someone asked if I was still looking for participants.

Using team members as gatekeepers meant that they made the initial approach to potential participants. This meant that their enthusiasm for research and interest in the study affected their willingness to approach people, and also they gave the initial information to participants. My only control was the written information they gave to participants. On my first visit to Simon to tell him about the study he said

‘Oh I thought it involved drugs. Alison (nurse) said something about a placebo’

My relationship with Alison gave me confidence that this was unlikely and his wife confirmed this, but it illustrates the vulnerability of the researcher to the gatekeepers. The ethical issues raised by this are discussed in Chapter 7. I was also aware of at least one occasion when one of the nurses used a previous professional relationship with me to explain my credentials to a potential participant. This could lead to a confusion of my role as researcher or nurse that was to pre-occupy me throughout the fieldwork.

4.5.3 Participants

The initial study design specified five people with dementia and a significant other as my participants. The professionals were to be recruited as members of focus groups. As the study developed I was able to recruit the individual professionals who were involved with the person with dementia, which helped to contextualize the study.

it is useful to see qualitative sampling as an *organic* practice, in the sense that it is something which grows and develops throughout the research process

(Mason, 2002: p127)

The key participant in this study was a person with dementia who had experienced hallucinations. It was essential that they were identified first, but also that they had a carer who was willing to take part in the study. Inclusion criteria for all three participants of the triad were linked in that they were dependent on a relationship with each other.

4.5.3.1 **Inclusion criteria**

My inclusion criteria for people with dementia were

- Diagnosis of dementia
- Living in the community
- They had experienced hallucinations
- Capacity to give consent
- Would not be upset discussing hallucinations
- A significant other who was willing to participate and had capacity

Inclusion criteria for carers were

- They were a significant other nominated by the person with dementia
- Capacity to give consent

Inclusion for professionals was

- Member of a community mental health team
- Either a trained nurse or occupational therapist

4.5.3.2 **Sample**

My final sample comprised three people with dementia, their significant other and their mental health professional. Deteriorating health meant that at least two people who the teams had thought may be suitable had ended up in hospital before they could approach them. Another two people who I telephoned did not want to participate. The table below shows the final participants in their triadic relationships. The names used for all participants in this thesis are pseudonyms. Each participant is described in further detail in the separate case study chapters (Chapters 5,6 & 7).

Table 1: Case study 1

Pseudonym	Gender	
Graeme	Male	Person with dementia
Lesley	Female	Daughter
Kim	Female	Nurse

Table 2: Case study 2

Pseudonym	Gender	
Dave	Male	Person with dementia
Joan	Female	Wife
Alex	Male	Nurse

Table 3: Case study 3

Pseudonym	Gender	
Simon	Male	Person with dementia
Jeanette	Female	Wife
Alison	Female	Nurse

The small number of people who were eligible for the study and difficulties in recruitment meant I had no control over the gender of any of the participants. All three of the people with dementia were male, two lived with a spouse and the third lived alone. The two married men nominated their wives as their significant other

and the man who lived alone nominated one of his daughters. All the mental health professionals were nurses, two female and one male. I did not choose to ascertain any stage in dementia, nor MMSE score (Folstein et al., 1975) for any of my participants as I believe this represents an unnecessary value judgment on their cognitive deficiency.

The participants were selected because of their characteristics; they reflected features of the population I wanted to study. I am not making any claim for statistical representativeness. The most important consideration, as Flyvbjerg (2006) suggests was not the sampling of attitudes but the opportunity to learn most. I excluded people with dementia who would become upset at talking about their hallucinations, but the professionals supplemented this absence with discussion of these people. Although this gave a different perspective it did provide data on how nurses deal with distressing hallucinations.

In the following sections I describe the data collection methods I used in the study. I could not see the things that my participants saw, nor could I be there when they occurred, this would involve participant observation that would be far too intrusive in the lives of people who were living in their own homes. One of my participants, Dave did have a hallucination when I was present; this incident is discussed in Chapter 6. The main method data collection method I chose was to interview participants.

4.6 Interviews

Interviews have become ubiquitous in popular culture as a standard narrative through which individuals express their identity (Back, 2012). They probably remain the most prevalent method of data collection within qualitative social research (Legard et al., 2003).

Despite their similarities with everyday conversations, Rubin and Rubin (1995) point to the difference in purpose and the role of the participants. Simons (2009) outlines four purposes for using interviews in research studies

- Document the perspective of the interviewee

- Method of active engagement
- Flexibility
- Potential for uncovering unobserved feelings and events

I would argue that clinical interviews within mental health nursing have an almost identical purpose and so it is a method that is very familiar to me. This put me in a conflicted position at times and needed to be addressed through a continued attention to reflexivity.

4.6.1 Practicalities of interviews

There are different ways of conducting interviews, but I chose unstructured interviews as the main data collection method to allow participants to construct their own narrative in the way that they wanted. I believe that unstructured interviews can be less stressful for people with dementia who may associate very structured interviews with being tested. I wanted to elicit in-depth answers from my participants living with dementia about their hallucinations within the contexts of their lives. This, alongside a need for flexibility, meant that I decided to interview people a number of different times.

I introduced the topic with a broad statement, telling people what I was interested in, and allowed the conversation to follow the path dictated by participants. The aim of the interviews was to obtain rich in-depth data, and asking the same questions of everyone is not going to achieve this (Rubin and Rubin, 1995). As a result we covered a wide number of subject areas. This approach meant that the research relationship was central to my research process. My style of interviewing was informed by my clinical experience and an ethic of care framework.

I offered people with dementia the option of being interviewed alone or with someone else present. Simon wanted his wife to be present and so all of his interviews were with Jeanette. She helped him at times when he asked her directly for assistance

Simon: yes but you weren't with me then were you?

Jeanette: yes

Simon: oh I don't remember you being there

Jeanette: cos we were lying in our bed in (placename) and the window, we've got Velux window and you were telling me about the little man, did I see the little man

In this conversation Simon positions himself and is positioned by Jeanette as forgetting.

The carers were also offered the option of being interviewed alone. They all chose to be interviewed with the person with dementia. Lesley, Graeme's daughter said she would not be saying anything that she would not say if her dad was not there. These interviews started with the person with dementia being quiet but inevitably they ended up in joint discussions. The joint interviews cannot be said to represent whole conversations between the person with dementia and carer. The person with dementia had already been interviewed at least once, and was aware that I was interested to know the understandings of their carer in this interview. Nurses were interviewed once in their offices. The following Table shows the number of interviews conducted for each participant with dementia and carer

Table 4: Interviews with people with dementia and carers

Pseudonym	No of Interviews	Place	Time frame
Graeme	3	Home	4 months
Lesley	1	Graeme's home	
Dave	3	Home	2 months
Joan	1	Home	
Simon & Jeanette	2	Home	2 months

It was important to me to develop trust and rapport with my participants although as discussed later this resulted in some ethical dilemmas, when I felt conflicted about my roles. Interviews are not innocent. I felt comfortable in an interview situation as the majority of my clinical work was conducted through interviews. This led me to collect data through interviews that may reflect mental health professional interviews.

My experience as a nurse may have led to me being skilled at extracting 'tales of suffering' during my interviews, Steedman (2000) calls these enforced narratives and compares their intrusiveness to statistical data. This causes an on-going ethical dilemma between portrayal and betrayal.

4.6.2 Data management

All the interviews were audio recorded; I kept the vernacular in the transcripts as it was more faithful to the person being interviewed. Field notes were written as soon as possible after each visit and also for any telephone contact made with participants. These notes were used to inform the analysis; I recorded any non-verbal behavior and also my immediate reactions to the encounter in them. I wrote field notes after a trip out with Graeme for lunch, and was able to record my thoughts on his difficulties negotiating space.

I transcribed all the interviews verbatim myself, and included transcription notation as suggested by Silverman (2001). In the quotations used in this thesis I have often added punctuation and left out pauses and changes in tone to make it easier to read. This process was time consuming but I thought it would allow me to see time lapses and changes in pitch and tone that might inform my interpretation. I do not think it was necessary to use this much detail in transcription given the analysis I chose. It was more likely to reflect on my position as a novice researcher, who does not want to leave anything out in case it may be important. Doing my own transcription enabled me to spend time identifying and listening to the different voices, which helped to inform my analysis.

4.7 Interviewing people with dementia

Interviewing people with dementia may pose challenges related to their cognitive difficulties. I have a lot of experience speaking to people with dementia and used clinical skills such as active listening to facilitate interviews. I interviewed all my participants with dementia in their own homes as they felt more comfortable there and had more control of the environment (Clarke and Keady, 2002). Flexibility can be especially important with people with dementia. People may become tired more quickly, concentration may fluctuate and some of my interviews lasted for a shorter period, than others. Graeme lived alone and I always telephoned him before I went to ensure that he remembered I was visiting, and also to see if he still wanted to speak to me that day. There were a number of times when he said he did not feel well enough and so we changed the day.

Although normal talk involves confusions and is reliant on context, when this happens in dementia, people may be positioned as ‘problems’ (Shakespeare, 1998). Conversation may be more fractured in dementia, Dave had particular difficulties associated with his Parkinson’s and his speech tended to tail off and become much quieter. He had attended a course in speech therapy that taught him some techniques for dealing with this and it was important to give him time and listen closely to his speech. Simon too told me he felt he had difficulty in expressing himself. I felt I was less skilled in recognising Simon’s difficulties; it was only during our third meeting that he told me this. I had felt earlier that I was not establishing a good relationship with him, and contrasted my interviews with Simon, with my interviews with Graeme and Dave. I attributed my discomfort to my incompetence as an interviewer. On reflection, this highlights the power differentials between someone with dementia and someone who does not have a diagnosis, as well as researcher and researched. I had ignored the importance of time in establishing a relationship, and not recognised his struggle to find a voice. Had I not been so uncertain about my own position as a researcher, I might have spotted other clues such as his desire to be interviewed jointly with his wife, and that his interviews were shorter than those with Graeme and Simon.

Despite some of their difficulties with language, I was struck by the determination of my participants to be heard. Dave in particular had obvious speech problems and while watching and listening to him, at times I felt uncomfortable because of the effort he was expending. It could be challenging for him to sit still and his speech was often circumlocutory but this did not impede his desire to communicate.

Dave: then there's the social aspects of it and having trouble keeping up conversations you know

A focus on the discursive or textual elements of storytelling may result in people with dementia being viewed as less than competent, but acknowledging the performative or interactive aspects changes the way we listen (Hydén, 2013). Dave did not need me to help empower him; he was able to do this for himself. My interviewees were generous with their time and in sharing their experiences.

4.8 Creative narrative

There has been an increasing interest in the use of creative arts within social science, and the amount of research using creative methods has begun to flourish (Simons and McCormack, 2007). Visual images have been used to illustrate anthropological and sociological research for some years, although the use of photographs in anthropology in the past has been criticised for exoticising the Other (Riessman, 2008, Saïd, 1978).

The Visual Sociology Group identifies three uses of visual methods in sociology

- Collecting data using visual means
- Studying visual data and reading them as texts
- Communicating research findings with images and media other than words

(Visual Sociology Group BSA, 2013)

It is argued that creative knowing accesses different ways of knowing and allows connections in different ways. It can also help to clarify thinking and stimulate ideas (Bartlett, 2013, Kontos et al., 2010).

I used poetic form within my analytic approach to re-present the words of the person speaking and to free me to think differently about my data. This process is discussed in section 4.10.2.2. I also used some visual data in my study. The illustrations are at the start of each of the cases in the next three chapters. This was done in different ways for all participants with dementia and was very limited within my research,

The illustrations for Graeme (Figures 2 & 3) and Dave (Figure 4) were done by an illustrator (Middleton, 2011), who I knew, and at different times during my contacts with them. Graeme had previously told me about his hallucinations, and with his permission, the illustrator was given a few short extracts of his description of his hallucinations prior to the start of the study. They are used in this thesis to illustrate his hallucinations. He was shown these illustrations and one in particular (Figure 3) he described as just like the experience he had had. I found this surprising as to me it was not a realistic picture. The illustration before Dave's case description was done by the same illustrator, who in this instance was asked to draw activity in trees, either boys in bright uniform or a play. The illustration produced allowed me to think through the data in a different way. Simon drew the illustration before his case study (Figure 5) prior to meeting me, and so was not produced for the study at all. It contributes to my knowledge of how he experiences his hallucinations, and is reproduced here with his permission.

I am not assuming that a visual representation reflects reality any more than a verbal representation. I do however agree with Mannay (2010) and Simons and McCormack (2007) that creativity can help to fight familiarity and allow you to connect in different ways. My use of the visual representations was more interpretive than analytic. It allowed me to access intuitive understanding, Simons (2009) describes this process as like dancing with data, looking for connections and feelings.

4.9 Researcher and/or nurse

The notion of impartiality in interviews has been widely refuted; I am implicated in the process of constructing interviews, as in the whole research process.

We now recognise that the personal account, in research interviews, which has traditionally been seen as the expression of a single subjectivity, is in fact always a co-construction

(Salmon and Riessman, 2008: p80)

This extract from Salmon is written in the context of the difficulties of interviewing people whose narrative may be challenging. She calls for even more attentiveness as a listener, including to the importance of non-verbal language. Riessman (2008) follows this piece up by throwing out the challenge to integrate visual data.

Acknowledging my own situatedness is an important aspect of my theoretical stance see Chapter 3. The researcher brings a number of roles to the research relationship (Reinharz, 1997). My role as both a nurse and researcher was present throughout the study. It was something I was aware of in my struggle to locate myself within certain theoretical perspectives, but during the data collection period it surfaced especially within my relationships with other people. As I believe that ethics occurs within relationships rather than as disembodied universal principles, my research relationships sometimes initiated an ethical dilemma.

The Ethics Committee written response to my application acknowledged that I was an ‘experienced community psychiatric nurse’, and as discussed earlier my previous relationships with mental health teams may have facilitated my access to them. I used skills from clinical practice in interviews with people with dementia and their carers.

I was honest with participants about my status as a nurse although they had all been given this information by the gatekeepers. Although I had not been his community nurse, Graeme knew me in this context in the past, we had met regularly at a dementia café and a campaigning group. My work as a nurse has resulted in my being privy to intimate knowledge of a person’s life, often in a very short space of time. I am used to acting in a therapeutic role. In my role as researcher the main purpose of my relationship was not therapeutic but data collection and this did lead to ethical conflicts for me as described in Graeme’s story (Section 5.5).

4.9.1 Research relationships

The insider/ outsider opposition can provide a useful backdrop to the different roles that may impact on research studies, although an absolute dichotomising should be treated with caution (Hammersley and Atkinson, 1995). The insider/outsider debate has resulted in what have been called insider myths and outsider myths. The outsider myth asserts that only researchers who are objective and distanced from a group can conduct valid research with that group. The insider myth counters that a distant and objective researcher cannot understand the true character of a group. (Mannay, 2010).

A consideration of proximity as it impacts on research is important, as discussed previously, knowledge is situated, it comes from somewhere (Mannay, 2010). In my study it is most obvious in relations with community mental health professionals. I used the term hallucinations in the information sheet I gave them, which positions me as one of them. I worked as a community mental health nurse for many years so I am, but am no longer one of them.

The literature on close relationships within research can fail to distinguish between 'going native' and research within an already existing relationship. Postmodernism warns against assuming dichotomies like insider/outsider as we are all members of a multitude of communities at the same time (DeLyser, 2001, Taylor, 2013a). Our selves are shifting and partial and we take lots of selves into the field (Coffey, 1999) I had been a community mental health nurse but I was now a researcher and I know that some of my ex-colleagues had always thought there was a gap between theory and practice and criticised academia for not reflecting the 'real world'.

Writing in support of insider research, benefits that are identified are that it can enhance access, the insider will speak the same language and will be able to reach a better understanding (Taylor, 2013a, DeLyser, 2001). As stated earlier, I think that the nurses knowing me did help me to gain access to both people with dementia and also to community mental health professionals. I chose the expression hallucinations assuming they would have a similar understanding of its fluidity to my own.

Disadvantages of insider research include a concern that participants may expect the researcher to agree and sympathise with them. There may be an assumption of shared knowledge, and the respondent may become frustrated if the researcher asks questions to which the interviewee is aware they know the answer. (DeLyser, 2001). My interviewees often said 'you know' suggesting to me that they supposed we had shared knowledge. I think that using informal interviews helped to prevent irritation, although it may also have meant that I was too close to them to look for implicit knowledge. It is difficult to recognise knowledge that is taken for granted as an insider. What Law (2004) has called absence that is othered, as discussed in the last chapter, may not be recognised because it is seen as irrelevant or forgotten. I tried to be aware of my dual roles throughout the study by using a reflexive approach. My choice of data analysis which requires consideration of the researchers' response to the narrative helped in this process.

Kim, the nurse with whom I had previously worked most closely, emphasised her individual approach to care, and at one point distanced herself from me

you and I would do things differently to the same end point
and probably reach the same end point but we would go
about it in a slightly different way .

I was surprised by this, and think on reflection it was because I struggled to make the familiar strange.

4.9.2 Reciprocity

The importance of reciprocity was something I had to learn as a researcher, working as a nurse I had seen my role as providing care within a relationship. As a researcher I was not sure what, if anything, I was providing for my participants. Ben-Ari and Enosh (2012) point out that the conventional way of understanding power relations in research is as a dichotomous relationship. Relations are viewed as asymmetrical, in favour of the researcher, who holds the power to develop knowledge, using the researched. The potential for exploitation afforded by this position has led to attempts to shift the unequal balance by empowering the participants. Another response is to address the shifts within the power enacted in relationships. The

person who is participating has knowledge during the data collection period and knowledge is jointly created. They suggest that reciprocity provides a better solution than equality with both researcher and participants receiving different gains. For the participant this may be telling their story to an empathic listener, contributing to new knowledge, to help others, or being able to assert a marginalized voice. This may be especially relevant with people with dementia whose voice can still be marginalized. Two of my participants with dementia and two carers stated that they hoped it would help someone else and one carer expressed the opinion that

as I say it's actually helpful for me. I think that's one of the big things is when you're trying to cope with something, with a member of your family being no well is nobody seems to listen. Nobody, nobody seems interested

Joint interview Lesley and Graeme

I can accept Ben-Ari and Enosh's argument but still found it difficult to process emotionally. As they suggest

Possibly scholars and researchers who emphasize equity are driven by feelings of guilt and discomfort in overbenefiting from the exchange, and by collective guilt over abuses of power by other researchers

(Ben-Ari and Enosh, 2012: p6)

With Graeme this guilt and discomfort surfaced following a concern I felt during one interview, that I was just using him for my study. Following discussion with my supervisor I realised I could offer him something and took him out for lunch. He found it difficult to go out alone and told me what a chore it could be for him to cook. Although this helped, it still caused me difficulties and is discussed further in the next chapter (Section 5.5). There were a number of occasions when participants asked me questions about dementia, and I answered from my clinical knowledge, but felt that I should not be doing this. My socialisation into viewing a researcher as objective caused me to struggle with these issues.

4.10 Data analysis

The process of gathering and analysing data contributed towards what Birch describes as ‘my journey of self-discovery’ (Birch, 1998: 171). Like many aspects of the research process, analysis is not a discrete element but continues throughout, from the initial contact, transcribing, data gathering and writing up.

The analysis I chose to use was voice centred relational method (Brown et al., 1989, Mauthner and Doucet, 1998, Doucet and Mauthner, 2008). This is a narrative analysis that was developed out of an ethic of care approach and identifies multiple voices.

4.10.1 Narrative analysis

Riessman (2008) suggests that there are 3 main types of narrative analysis

- Thematic analysis
- Structural analysis
- Dialogic/ performance analysis

Thematic analysis concentrates on the themes that emerge from the data, with little emphasis on how the narrative is spoken or written, or the local contexts of the narrative. Structural analysis is concerned with the way the narrator uses speech to convince the listener. Dialogic/performance analysis stresses the importance of the social context in which the narrative is performed in interaction with others. With thematic and structural analysis the voice of the interviewer is absent from the text but with dialogic/performance analysis the voice of the interviewer is important, as they are ‘implicated in the storytelling’ along with the reader. In comparison to the other two categories it is ‘rather a broad and varied interpretive approach to oral narrative that makes selective use of elements and adds other dimensions’ (Riessman, 2008 p105). These approaches often use a wider definition of narrative than approaches such as structural analysis.

A dialogic/performance approach analyses how identity is constructed within performance and can be used in individual or group interviews. I used a relational,

voice centred analysis which belongs within a dialogic/performance type of analysis (Riessman, 2008).

4.10.2 **Voice-centred relational analysis**

Analysis was based on the voice-centred relational method of analysis as devised by Brown and Gilligan (1992) and developed by Mauthner and Doucet (1998). This analysis is underpinned by an ethic of care understanding (Mauthner and Doucet, 1998). Voice relational method was developed by Brown and Gilligan (1992) as a way of analysing the data from their longitudinal psychological study of adolescent girls. 'Voice' is the ability to make one's own feelings and experiences known and heard (Clare and Shakespeare, 2004). Brown and Gilligan viewed the approach of adolescence as a crossroads between childhood and adolescence.

A listeners' guide was developed, informed by both clinical and literary theory, which acknowledges the interactive nature of the research relationship, and the multi layered nature of narrative. It involves a number of sequential listenings which allow the multiplicity of voices of the narrator and listener to be heard. Using this method Brown and Gilligan (1993, 1989) identified psychological and political resistance in the adolescent girls. They exhibited psychological resistance to the dominant culture by struggling to ignore their feelings and exhibiting confusion. Political resistance was identified in their struggle to express emotions and openly disagree with others. Confusion can be something that people with dementia struggle against and Shakespeare & Clare (2004) suggest

For the person with dementia in contrast it seems that the focus of 'psychological' resistance is to fight against developing confusion

(Clare and Shakespeare, 2004: 227)

The method requires four readings or listenings of the interview data. Gilligan et al (2006) feel that the use of listening, rather than reading guide recognizes the active involvement of the listener as well as the speaker.

It assumes that there will be simultaneous voices from the same participant ((Balan, 2005). In the separate listenings of the data, the listener attends to different voices. I used a checklist developed by another student based on the work of Brown and Gilligan (1993, 1989, 2006) and Mauthner and Doucet (2008, 1998) to assist with analysis (See Appendices 7 & 8). I changed 'cancer victim' in her original and replaced it with 'person with dementia'. Data analysis is often a mystical part of research; I like the structure of the different readings, but also the flexibility of acknowledging the interpretation of the researcher. Although the readings or listenings are separated, they are not meant to stand alone, and I found they did in fact all build on each other in an iterative process. The development enabled me to keep the narrative of one person together. I found it to be a time consuming but worthwhile process. It was similar to my approach to clinical work, although as a clinician one does not have the luxury of immersing oneself in the data to such an extent. It resonates with the values I tried to bring when working of seeing the person as a whole, rather than just the diagnosis.

There were however difficulties at times in following the speech of some of the people with dementia. This led to some degree of difficulty in my part in knowing how to analyse parts of the interviews and possibly resulted in more creativity than analysing a conversation with someone who does not have dementia. People with dementia can be disadvantaged in a conversation with 'normal' speakers as they are less able to follow the conversational rules (Shakespeare, 1998). An example of this was apparent in joint interviews when although an attempt by the carer to correct the person with dementia can be seen as silencing them, it can also be seen as rescuing them and allowing them to continue.

I was not seeking to obtain an objective truth. This approach was an appropriate one to my study because it is a narrative approach to data analysis. As discussed earlier, along with many nurses, I am aware that my clinical practice has involved me listening to and interpreting stories, especially latterly of people with dementia. It resonates with my belief in the multiplicity of voice and I like the fact that the narrative is kept intact rather than immediately reduced by cutting it up. As it was developed to allow the voice of groups who are marginalized to be heard, it would

seem an appropriate approach to hear the voice of other such groups. I am aware of two previous studies with people with dementia that have used this method. Proctor (2001) interviewed four women with dementia about services and analysed the data using voice relational methodology. It fitted with a person-centred approach towards people with dementia and identified issues of gender and power. The other study used voice relational analysis along with conversational analysis to examine how people with a recent diagnosis of Alzheimer's disease and their spouses negotiated living with the diagnosis. The researchers set up conversations between both parties lasting only 5 minutes and then analysed them. Although the conversations were extremely short they enabled the researchers to begin to identify the voice of the person with dementia, the voice of the relationship and the societal discourses about dementia (Clare and Shakespeare, 2004).

4.10.2.1 **1st reading**

The first listening consists of two parts. The first part focuses on the overall story or plot. It asks us to attend to what is happening in the plot and locate the narrator. What are the main events, who are the protagonists, are there any recurrent themes, words or metaphors? I created word clouds to identify the words that were used most frequently in the interviews. An example of a word cloud is attached (Appendix 9).

The second part of the first reading is the response of the listener to the story. This allows the reader or listener to reflexively examine their response, from 'the privileged position of interpreting the life events of another and to consider the implications of this act' (Brown and Gilligan, 1993 p15). There has been a common assumption that people with dementia are unable to speak for themselves and often other people are asked to speak for them. This approach assisted me in thinking about how my feelings may affect my interpretation. An important aspect of this part of the analysis process for me became the reflexive element. I found it relatively easy to question myself during the course of this activity but much more difficult to write about this process, and put myself into the data analysis. After all I was a nurse with some aspirations to academia, and academic writing is in the third person; writing about myself feels self-indulgent. Again this demonstrated my difficulties in

extricating myself from my socialization. Perhaps my writing about my own emotional reactions contributed to the disempowerment of an already disadvantaged group. In my role as clinician I felt powerful, I have knowledge, but in my role as a researcher I was less sure. I found it easier as the research went on, to see the shift in my role from listener to interpreter.

4.10.2.2 **2nd reading**

In the second reading the listener attends to the voice of the self or selves who are talking. Focusing attention on how the person speaks of themselves allows space for the participant to speak before the researcher allocates the data to 'either our own ways of understanding or into the categories of the literature in our area' (Mauthner and Doucet, 1998 p130). It allows the 'I' to speak before the researcher speaks for the participants.

Sabat (2001) describes three aspects of selfhood in which Self 1 is the self of personal identity and the site of a continuity of self. He cites the use of personal pronouns such as I and me as evidence of this.

In the second reading, the researcher goes through the transcript and identifies all the times that the participant uses 'I' as a personal pronoun. While listening to how the person was talking about themselves, I used a coloured pencil to underline where the person uses I or me. The first person pronouns 'I' and 'me', as well as 'we' and 'you', when it seemed to be used for the first person, were underlined along with the verb, and other words that seem significant. Some researchers have done this and then taken them out to produce I-poems' (Balan, 2005).

There is obviously a degree of flexibility and interpretation involved in this stage, some other researchers have strictly used 'I' but it seemed to me that other words could be describing the Sense of Self 1 as defined by Sabat. I am persuaded by the argument of Edwards & Weller that

'taking account of people's different speech patterns to produce you-poems or me-poems, or indeed we-poems, is equally enlightening about senses of self'

(Edwards and Weller, 2012: 208)

I wrote I- poems for each participant. These 'I' phrases were cut and pasted in the same order as they were spoken in a separate I-poem document. They were split into stanzas based on what seems to be a change of subject or mood. What is retained in each phrase and how this is split is a subjective decision (Balan, 2005). I found the I- poems especially helpful in attending to emotional issues. This was probably because of the focus on how the person is talking about the self, which as a mental health practitioner may well be something I have been trained to pick up. A disciplinary background will mean that different functions of a narrative will be privileged over others (Rauol et al., 2007). The other reason it picks up on emotional issues is that this is what poetry does; it engages the reader and writer in feeling as well as recording experience.

As Edwards & Weller point out

'in contrast to a stress on the creation of meaning through thematic analysis, its initiators pose I-poems more as concerned with assessing meaning in relation to self'

(Edwards and Weller, 2012: p204)

This process seemed to me to pare down the data to the essential emotional meaning of how the person thought of themselves. The longest I- poem by far was the interview that had the most emotional content and was the most difficult one for me. This second reading of the data was the one on which I spent the most time. One of the things it did not pick up was humour, so it is important that the narrative is kept together as this can be seen in the whole readings. Extracts from all the I- poems are used in the case studies in the following three chapters.

The I-poems were created directly from the words of the participants and were not written in the same way as well-crafted poetry; however I found that the Poet Laureate Carol Ann Duffy's words were still germane

Poetry, above all, is a series of intense moments-its power is not in narrative. I'm not dealing with facts, I'm dealing with emotion

(Duffy, 2005-2010)

4.10.2.3 **3rd reading**

In the third and fourth readings I followed Doucet and Mauthner (2008) and read for the way the participants experience themselves in relation to the wider society in which they live. Gilligan et al. (2006) read for contrapunctual voices in the third reading but I was interested in listening for identity following Sabat's (Sabat and Harré, 1994, 2001) concept of Self, and the Doucet & Mauthner reading was more appropriate for this task.

In the third reading I concentrated on how people talked about their relationships, this could be with friends, family, colleagues, other people with dementia, health professionals in the case of people with dementia and people with dementia in the case of mental health nurses. Again these instances were underlined with a different coloured pencil in the interview text.

4.10.2.4 **4th reading**

In the fourth reading many researchers have listened to how participants position themselves in relation to dominant discourses within society. Sabat's (2001) Self 3 is the self that requires co-operation from other people. It consists of the social personae that we construct e.g. father, teacher, a competent person and is therefore the most vulnerable in the person with dementia, who may not be accorded these personae by society or indeed those with whom they are in relationships. I listened for the cultural contexts and social structures (Mauthner and Doucet, 1998) within which people were speaking. For my respondents this was mainly in the way they viewed dementia or old age, and for the mental health professionals it could also be about the health care system. Sometimes this method resulted in sections being underlined with a number of different colours.

I used the method with all of my participants. This method has been used with people who struggle to be heard within the dominant discourse of society but also with professional groups such as nurses and with couples of a person with dementia and their spouse (Balan, 2005, Letvak, 2003, Clare and Shakespeare, 2004).

When I analysed the joint interviews I did this separately for the couples apart from Jeanette and Simon who I saw together on each occasion. Their interviews were noticeably more co-constructions than the other joint interviews and it made sense to keep their contributions together. I did split them up at one point, but ended up analysing it as a joint interview. When I produced the I- poems for these interviews I distinguished between their contributions by italicising one of them.

4.10.3 Dancing with the data

From all these readings of each person, I wrote triadic cases that included the voices of each of the participants in the triad. This process of organizing and making sense of the data as individual cases was followed by a more interpretative phase. I had kept field notes throughout the data collection and the voice centered analysis, which was a mixture of reflections following each contact, and also any developing thoughts on interpretation. At this point I used the visual and written data as a more hermeneutic process, to understand the whole, by making sense of the parts (Simons, 2009). This involved immersion in the data, making mind maps, physically moving it around, being surrounded by the visual material and engaging intuitive and cognitive ways of knowing, including the research issues of identity and multiplicity of hallucinations (Appendix 10). Narrative understandings of hallucinations of people with dementia and carers were related to narrative identity. The nurses in the study held together multiple understandings. Finally I developed a way of understanding hallucinations utilizing the theory of liminality.

4.11 Conclusion

Data collection was not always easy or comfortable for me; it often caused me to rethink my assumptions as a mental health nurse and my relationships with people with dementia. My data analysis method helped me to address some of my assumptions but I recognise the impossibility of distinguishing them all especially at this stage (Mauthner and Doucet, 1998).

The case-study structure and narrative analysis allowed me to attend to the narratives of individuals. It enabled me to examine how people narrated their experiences within the contexts of their lives and relationships. People did not always talk

directly about their hallucinations, but the content of their narratives was a reflection of how they made meaning of their lives with hallucinations and dementia. The three case studies follow, they are not truth or reality, but they are my narratives of my interpretations of the cases. In the cases that follow I have tried to avoid any academic references, as I want the people to be able to speak for themselves, albeit within the confines of my narrative. I have retained much of the linguistic formations of the participants, but also using extracts from I- poems, I have extracted parts of their dialogue. The cases are written in the order that I interviewed people and I have tried to write them to give a flavour of the voice-centred analysis process but also the development of emerging interpretative ideas. I have included reflections on myself as researcher throughout the cases.

Graeme



Figure 2: The cat



Figure 3: Making the bed

Illustrations R Middleton

5 Graeme, Lesley and Kim

In this chapter I present the first case, that of Graeme who has dementia, his daughter, Lesley and Kim, Graeme's community mental health nurse. They are presented separately although they refer to each other throughout the chapter. The final section of the chapter is a reflection of a conflict that arose for me during an interview with Graeme causing me to consider whether I was a nurse or a researcher.

I have not presented the cases as four separate readings but I hope the readings are apparent through the case descriptions. Extracts from the I- poems are used throughout.

5.1 Graeme's realities: 'a hypochondriac a wimp or completely mad'

sometimes I feel fine and I can just go ahead and do things
but most times I feel I cannae and whether it's as I say
whether it's being a wimp or a hypochondriac or just off my
head I don't know. I cannae I can not fathom it out how I live
my life

I knew Graeme from the past, I had met him at various services set up by an ex colleague and I, for people with dementia. When we first met he lived with his wife but she had since died. He now lived alone and had two daughters living locally with whom he had regular contact. He is in his seventies.

I knew that he had had a diagnosis of Lewy-body dementia. A few months prior to our research contact the certainty of this particular diagnosis had been questioned, and he had been told that although medical professionals accepted that he had some type of dementia, they were unable to give it a specific name.

The year before I started my PhD I had spoken to him about my interest in this area and he had vividly described a variety of hallucinations. Some were recurrent but others had happened only once. A large cat with a fluffy tail was a frequent 'visitor' to his house; he knew this was not real but was very tolerant of its presence as it did not cause any problems. It just sat on the settee. It seemed apparent that some of his hallucinations were more frightening, such as when he had seen people massing in

his hallway like a political rally. Hallucinations were in fact the first indications that he was having any difficulties. He described occasions when his wife was still alive and before his formal diagnosis when he would ask her who the people were in the house. An example of this type of episode was that he had returned home one day and seen two old women making the bed. He asked his wife who they were and she told him there was no-one there.

Before I began my study he had accepted that his hallucinations may not be what other people were seeing. He described how he had learnt if he saw something unusual to walk out of the room to try to establish if he was hallucinating. He would try to work out logically if a situation could be correct. He gave an example of seeing a group of ex-neighbours in his living room; he went into his kitchen, made himself a cup of tea, and reasoned that the people in the living room were not there. He reached this conclusion because the children he was seeing would now be in their thirties rather than the age he was seeing them.

During my research contact with him he was more concerned about other aspects of his dementia that he was finding distressing than his hallucinations. During my interaction with him his physical health deteriorated causing him difficulties. Hallucinations may be the more extreme manifestations of his dementia, as they do not fit in with most people's views of reality, but for someone like Graeme they did not present the greatest disruptions to his life.

5.1.1 Negotiation

In some ways our earlier relationship made me less anxious about my first 'research interview'. However, my role was now different and I was not sure how we would handle that change. I think it just offered me different challenges. I was fairly certain that he would agree to be part of the study, partly because we had previously discussed his hallucinations but also perhaps because he knew me. When I went to discuss the study with him he told me 'if I can help just one person'. He launched into a description of an episode of hallucinations using the term 'hallucinations' spontaneously. This had happened approximately two years ago when he had gone away on holiday to a convalescent home for the industrial group he had worked with

in the past. He had woken up during the night and seen people with Doberman dogs. He had been frightened by the episode and embarrassed at causing upset to other visitors. As a result of this experience he had telephoned his daughter and asked her to take him home because he knew that another episode of hallucinations would probably follow. He will no longer return to this environment because of this incident.

My second visit was to discuss signing the consent forms. I was struck by the contrast with my previous visit. This time he told me I had got him on a 'bad day, a bad week'; he had had a difficult holiday and described himself as doing 'stupid things'. I felt intrusive and concerned that he had been too polite to tell me not to visit. He said he still wanted to participate in the study and by the end of my visit he seemed noticeably more cheerful, telling stories of past achievements, such as doing a degree late in life and his previous sociability. This highlighted the need for process consent during my study and became the pattern for my on-going contact with him. Ethical issues are likely to be negotiated throughout the research process and the integrity of the researcher is the prime guarantee of ethical research (Murphy and Dingwall, 2007). One off informed consent is not enough to achieve well-being and this issue is perhaps more important in a study involving people with dementia.

In subsequent visits I telephoned on the morning of each pre-arranged contact to check that he still felt able to see me that day; there were days when he told me he was not feeling up to seeing me.

5.1.2 The setting

Extracts from field notes

There is a religious head on the outside of his door. I entered the hallway and was struck by how narrow it is. There are a Hoover and a mop in the hall. He had presumably been doing some housework, but I was aware how in that narrow space something like a Hoover appeared out of place and cluttered the space

We go into his living room. He always sits in a large chair by the window facing the TV and his music centre. The wall

facing him is covered with religious pictures and pictures of his family. I sit in a chair beside him as I feel it is easier to talk to him there, rather than from the other side of the room

On the way out of the house in the hall I was again struck by its narrowness and that there were photographs of his family and his degrees framing the walls. I remembered his story of frightening hallucinations of people in the hall and wondered if the people in the photos had been the people he had seen.

Graeme struggles with how to trust his own knowledge and the uncertainty of living with dementia. Hallucinations have become a part of his life and he has learnt how to cope with them but he finds it difficult to know what is real.

5.1.3 'I don't know, I don't know'

How does he know and what knowledge counts? Is it the things he sees or is it what other people tell him? Sometimes he does not know how to make sense of what he does. He uses the word 'know' frequently throughout the interviews, using in almost equal numbers 'know' and 'don't know'. He struggles to understand what is happening, frequently questions himself. There are at least 18 times in the second interview when the 'I' is prefaced with an interrogative word 'what have I done' 'why did I' and the word 'maybe' is repeated 49 times.

In reading for the 'I' I listen to the feeling, acting and knowing 'I' as the protagonist of the story. Knowing was countered with 'not knowing'. He is more often confused, less sure, can't remember. An I- poem crystallises the way he talks about himself. He starts with the voice of uncertainty 'finding it harder' then 'I don't know' six times. He silences himself rather than making mistakes 'I'm just accepting' 'I keep myself away from situations'. The voice of certainty is silenced by the voice of uncertainty; he suppresses his own certainty by acceptance 'I just accept it'.

I still have them

I'm finding it harder

I don't know, I don't know

I feel, I just accept it

Graeme, Lesley and Kim

I'm getting more I don't know

I'm in the house

I'm usually in the house myself

I feel, I used to see

I don't know

I'm having a hallucination

I find it harder

He finds it more difficult to know for certain and contrasts this with his life pre-dementia when he was certain and would argue for his own position. He can argue with the TV, it does not tell him he is wrong but not with other people, he needs more time now to make sense of things. He is more likely to accept the certainty of others who have told him he is wrong. Before dementia he had certainty, now he is unsure. His dementia is affecting his sense of identity, he frequently says 'I used to'.

Locating himself in time he compares himself with his past and with a possible future when he will be oblivious to the pain of his current confusion. He describes how he and his brother are very alike and his brother may be a connection with the Graeme who has changed

we were very alike. Both in looks and wer nature

A central metaphor is going to another place. This can be 'lovely' as when he went away spontaneously for a few days' holiday, and can be something he does to cope with his hallucinations. It is also something he thinks may take away the emotional pain he currently feels

maybe be better if I get to the stage where I don't know at all
what's going on then it wouldnae bother me

5.1.4 **A shrinking world**

His world has shrunk because of this uncertainty, so that he spends longer in the house alone 'I'm usually in the house myself' and relates to a smaller number of

Graeme, Lesley and Kim

people; his interactions are now predominantly with his family. He avoids going into environments in which he would previously have spent time, such as the pub.

Sleeping consumes a larger proportion of his time. Home is more secure than the world outside 'I'm better keeping myself in my ain wee cosy corner'.

The voice of the 'I' is often about coming home. Outside he feels he may be making a fool of himself and other people can see him lose things. This is not an easy decision and he becomes frustrated and blames himself for avoiding situations

sometimes I feel fine and I can just go ahead and do things
but most times I feel I cannae and whether it's as I say
whether it's being a wimp or a hypochondriac or just off my
head I don't know.

A number of times he says 'I'm not lonely, I like being alone' this however contrasts with his previous life when he enjoyed going out to pubs and concerts. He has been forced into this position by his dislike of making mistakes; 'I felt, I was inadequate' and 'I try to avoid getting into situations'.

He can still articulate strong feelings inside the house when he argues with the TV but outside, the struggle to know seems to take so much effort that he suppresses them. The feeling 'I' is often the voice of acceptance almost as if he has given up 'I just accept it' 'I think my mind gets so tired'.

5.1.5 Shifting boundaries

He struggles with the multiple realities he experiences, which have slippery boundaries. The voice of not knowing does not know what it all means. This uncertainty extends to what is happening to his body: what has happened to his walking stick which he has lost, his body is having difficulty knowing how to hold on to things.

He is preoccupied by the differences in his experience, and what other people see as reality. He tries to establish what is happening, knowing his experience can differ from consensus reality, and relies on his daughters for establishing the reality of situations

and Lesley says no you used that money for such and such.

Graeme's voice is the voice of uncertainty, his version of events is untrustworthy and so he accepts the knowledge of other people above his own. This is evident when he and his daughter are together, 'maybe I was maybe I've got mixed up again Lesley'.

On the other hand he wants other people to believe him; he says

I'm going to get CCTV put up in the house cos nobody but nobody would believe the things that I do.

He summons even more people to support his narrative, saying to Lesley 'it's a pity your mum isn't here'. Perhaps the community nurse could bear witness too 'in fact Kim will maybe remember about it cos (wife) told Kim'.

5.1.6 Living in relationships

He has a sense of himself as living in relationships, with his strong sense of attachment to his family. These are the dominant connections in his life. He is a widower, although his wife was still alive when his hallucinations first began. His daughters provide him with both practical help 'Lesley on a Sunday sometimes brings my lunch down' and 'Bridget usually does a big shop for me', and also feelings of security. His wider social circle has shrunk, but his family remain important and it is interactions with them he discusses most, both with his daughters and granddaughters. These relationships were brought up spontaneously by him rather than in response to any questions by me. His relationships with his family remain a core part of his identity, although he is more reliant on them now to tell him what is right

Lesley will tell you about these things. She'll say no dad that is the way things are.

When I interview his daughter Lesley, Graeme echoes what she is saying about his hallucinations and uses her to corroborate his version of events.

In many ways his relationship with his daughters is a reversal of the usual parent child relationship and is commonly described by carers of people with dementia, but he does not express any negative thoughts about this. He is able to talk to them

Graeme, Lesley and Kim

about his feelings and seems secure in his relationship. The way he talks of his relationships with his granddaughters is different, he talks about their activities and shows his pride in what they are doing, these relationships resemble the cultural norms of grandparent /grandchildren interactions.

5.1.7 Living in society

People as they get older are expected to get serious illness, but his anticipated narrative has been interrupted at a younger age. He struggles with the way that the expected narrative of his life has been interrupted by illness and now it is not even an illness that can be diagnosed with certainty by medicine. He had previously been given a diagnosis of dementia with Lewy bodies, but this has changed. It has been decided that this is not the correct diagnosis, although doctors are unable to give him a definitive alternative. Although he goes to doctors for their professional knowledge he also realises that they are unable to give him certainty ‘they don’t think that I’ve got what they thought I had’ and ‘there’s something going on but they can’t put their finger on it’.

He is aware of how dementia can be viewed within society and does not divulge his diagnosis to everyone, only certain of his neighbours know. He maintains his social etiquette to neighbours, when a neighbour comes to the door, the interaction which I overhear sounds empathic and interested in her difficulties, but when he returns to the living room he tells me he has no idea what she was talking about. He avoids situations where he may be shown to make mistakes, not wanting to get into situations where he may ‘make a fool of myself’. He does, however, have to balance this with a need to ask for help from family, but also from people like bus drivers.

He expresses a popular societal view of dementia with ‘if I get to the stage where I don’t know at all what’s going on’, but this is not currently his experience of dementia. This view would be frightening to many people, but to him at this moment it would eliminate the distress he feels, and he sees his dementia as a personal, rather than societal difficulty.

Although he sometimes focuses on his deficits rather than his abilities, which is the way dementia is constructed in society, he is critical of cognitive tests that are a standard way that people with dementia are categorized. He does not see it as indicative of how he functions

asking me who the Prime Minister is I could tell them almost every Prime Minister frae Gladstone and Disraeli

He resists the voice of the person with dementia who is confused, by explaining that he can answer these questions. Another way he resists, is describing that when he has time he can work out that he has not always been wrong, despite having possibly assumed that he must be wrong in the heat of the moment.

One might anticipate that he may benefit from mutual support with others in the same position, but he tells how meeting other people with dementia had made him feel inadequate. Comparing himself to others with dementia he has met through an advocacy group, he finds himself wanting, they 'seemed to be much more capable and adequate at dealing with what they've got to deal with'.

He contrasts his position with that of others with a chronic illness 'there's poor people suffering frae motor neurone disease or Huntingdon's or whatever'. This voice is a dominant one within society that supresses the individual voice of suffering, as others are always worse off, he has no right to complain. People with an illness like this are meant to be heroic and fight off their adversities. There is also a resisting voice, which says that this 'doesn't stop my difficulties'. It may reflect the dominant societal view of older people as having lived their lives but again he shows some resistance to this voice

I know as we get older and things happen, but I mean I'm no that old.

He judges himself as wrong to feel the way he does. He silences his right to talk about sadness 'I say get a grip of yourself Graeme think of other people that are got real difficulties in life'

5.2 Lesley: 'A dad's never scared'

Lesley is one of Graeme's two daughters, she does not live with him but has frequent contact, phoning him daily and taking him to appointments, as well as sorting out any mail which comes in. I offered her the option of talking to me separately or at her dad's house, and she chose the latter, saying she had nothing to say that she would not say in front of him. We met at his house during her lunch break from work. I was struck by the warmth expressed between Graeme and Lesley; there was a strong sense of emotional attachment between them that has not been changed by dementia.

5.2.1 A changing relationship

Lesley tells the story of change in her relationship with her dad. Her role has changed so that she is now providing practical help for him, as well as emotional support. There is sadness at the changes, and nostalgia for the previous balance in their relationship, but there are also benefits for Lesley

I mean in your day Dad you could be quite arrogant if somebody, if you disagreed with somebody, well you know that... whereas now if somebody says to him no I don't agree, it's quite good for me because he'll say to me this is what I think and I'll go to him well you know.

Although it is difficult for her to see her dad being scared, there is a grown-up voice here.

5.2.2 Family relationships

There has been a change in their relationship but there remains a strong relationality. She addresses him warmly, and calls him Dad throughout the interview. They both act co-operatively in trying to work out the reasons for his hallucinations. She assists him with his narratives

Lesley you're getting your story the stories are all getting muddled up

Graeme oh again here I go

They both acknowledge that there are difficulties for him in knowing what has happened and she is positioned by both of them as someone who keeps him in touch with the details of what has occurred

Lesley see you get this. All right where was this where did that happen?

Graeme Dublin

Lesley it didnae happen in Dublin

Graeme was it no that's where I thought it happened?

When Graeme talks of the emotional impact of his dementia, and a possible future in which it may be better when he is no longer able to remember, Lesley allows him to finish, but does not engage in this conversation. This is not far into the interview, and as it was set up to get her perspective, and she obviously has a lot to say, it would be foolish to assume that she sidesteps his emotional responses. She has previously acknowledged his anxious emotional response to hallucinations as being distressing for both of them.

The category 'we' is used for close family as this affects the whole family. It shifts from the 'we' of herself and her sister Bridget, who experience the greatest emotional impact of seeing the effort it all costs their dad

that's where Bridget and I struggle cos it's our dad. We're like we need to, it's like helping somebody with a stammer. You can see that it's painful

to the 'we' of husband and herself, who provide practical support 'we said to my mum look we'll take my dad away for a day'.

Other members of the family are safe, as they do not cause him anxiety, but don't have quite the same emotional ties as her sister and herself, so can respond without the same emotional cost.

and I think that's where my husband's good cos he obviously sees my dad as his father-in-law not as his dad

Graeme, Lesley and Kim

5.2.3 What is a dad?

Lesley has seen aspects of her dad that she had not previously known

I think the fear

I think that's a big thing

I think my dad being scared

I've never seen my dad scared

I think for me

I mean

She both knows, and does not know her dad, a dad should be in control and it is this change that is difficult for her

and it was a lack of control and I think that's a big thing for my dad my dad's always...had a good self-control with regards his thoughts and what he does and how he responds to situations..... then all of a sudden not being able to make decisions and not being able to understand things

Her sense of a 'dad' includes being in control, not fearful, able to make decisions, certain of his views, strong, a political guide, sociable and someone with whom you can have a trusting relationship. All these things are compromised in her current relationship with her dad because of his dementia and hallucinations

it is about you know I'm the child but it is about my dad having to say to me 'what do you think?'.

5.2.4 Trust

He is no longer able to trust his own knowledge and she has to explain what is real; she denies his perceptual reality and his temporal sequencing, but not his emotional reality. Trust is a recurrent word in this interview - his trust of his own knowledge and also his trust of her. How can she get him to believe her?

Lesley struggles to make sense of the disruption in her relationship with her dad. She talks about the lack of trust but then retrieves the relationship by saying that he doesn't mean it

Graeme, Lesley and Kim

I do feel there's an issue with trust and it and I know he
doesn't mean it.

She chooses to walk away from conflict when she knows it is irreconcilable at that
time

but if he has an argument me I've seen me just walking out
saying no that's it I'm no listening to it.

5.2.5 **More uncertainty**

The 'I' that is speaking is the voice of uncertainty as Lesley is living through the
experience of her father's dementia and hallucinations and trying to make sense of it.
Lesley uses the phrase 'I think' a lot suggesting she is not sure about what is
happening with her dad all the time. She is living with uncertainty and spends a lot
of time trying to work out what is causing his behaviour

but it's taken me 2 days to make sense of something you
know and it's and it is it's the second guessing and no being
sure

It can be a tightrope working out what is safe to say to him, and needs to be done by
someone who knows and understands him

you have to be so careful and so sensitive to lessen to reduce
the risk of him going 'there is something going on you know
there are people in the house'

She gives examples of her Uncle, Graeme's brother who is able to respond with
humour

my Uncle is very witty and my dad'll say well there
was a cow trying to get into my(.) bedroom window you
know this cow was and my Uncle turns it into humour.

People at mass, however, who are outside the family are not able to use humour, they
tell him these things happen to everyone. He sees this as a denial of his difficulties.
Family members have had to learn to gauge their use of humour. Lesley describes
an incident when she and her husband took Graeme away for the day and his son-in-
law's attempt at humour backfired as Graeme had been unable to take in the
subtleties and had taken him literally.

Graeme, Lesley and Kim

5.2.6 Shrinking world

I am surprised by the view they both expressed that a restricted social environment helps him to function, having always assumed that people who are socially isolated need more social stimulation. Graeme's social circle has become smaller and so demands on the family have increased

you look at they photographs and you see my dad and how sociable he was and how welcoming he was and things like that my dad has a very limited circle of people he'll mix with now.

there's a dozen by the time you count family Dad there's a good 12 people that he can say things to but outwith that I mean people that he sees at parish I mean when I was at mass on Sunday and they're like where's your man where's your dad I says no he was very tired yesterday so I think that's him like he couldn't say to them if he said to them if he said to them what a night

It is mainly family with whom it is safe to socialise, otherwise he becomes anxious about his responses. Lesley believes this anxiety increases his hallucinations.

if he went if he does something sociable and it's not in a safe environment..he will have a hallucination

They both valued a service provided by social care at the council that was personalised and flexible to his needs, but feel day care would not work for him.

Lesley see a day centre's no good to my dad

Graeme no I wouldnae go I'd get myself (the gaol)

Lesley if he went to a day centre we would have a rise in hallucinations.....if he went if he does something sociable and it's not in a safe environment

She believes that spending time with other people with dementia has been anxiety provoking for him, rather than supportive

Dad you used to have to go into the toilet and breathe because you couldnae cope with the social environment never mind about being incompetent and being different and being all the rest of it. Social environments and especially since

Graeme, Lesley and Kim

you've withdrawn from all these things you actually cope
better

5.2.7 Hidden work

Lesley situates herself and her sister in the position of carers. She is also situated in that position by services, but she becomes angry at the expectation that they do not need any help. A one to one service which she and her dad valued was taken away from them

nobody seems interested but I think it's about time you know
I mean the big thing for me is these guys that you had 2 hours
a week were interested were supportiveit took pressure
off me.

She was able to have 'quality time' with her dad as in a father-daughter relationship, rather than having to do the unseen work with him, of which other people are unaware. She speaks with the voice of injustice, acknowledging her own care needs, which are not being met by the statutory services.

She tells the story of the day to day difficulties of keeping her dad on track, work which is invisible to others who see him as someone who copes well

my dad can present quite well but it's taken me 2 days to
make sense of something

5.2.8 Making sense

Lesley accepts the medical view of dementia as a disease or syndrome and at times struggles with the authoritative view of science

I don't know if this is the science behind it

As I say this is maybe the science the brain sort of can't work
it out

Although she looks for explanations, she gives multiple reasons for his hallucinations - they can be caused by tiredness, change in routine, his dementia and also his memory difficulties. Equally appropriate responses are time and patience, limiting his social activities and humour.

She sees her dad's dementia, not as the societal view of dementia of total disintegration, but as differing from the norm

There seems to be this high functioning autism like my dad's dementia is like high functioning autism

But this does not negate the effect it has on him 'It's got this terrible impact on him'. This is not something immediately obvious to other people who do not know him, it is hidden, and impacts on her as a daughter

My dad can present quite well...but see my dad'll do things and I think do you know something it took me 2 days to get him there but then other people will think well done Graeme well done () but it's taken me 2 days to make sense of something you know and it's and it is it's the second guessing and no being sure and (0.1) I know they say it about dementia illnesses it is about regressing.

5.3 Kim: I find the brain fascinating

This interview took place at 8am in a medical centre where Kim has an office. Kim is an experienced community mental health nurse who knows me well, having worked with me for a number of years. She is a specialist dementia nurse and has been involved with Graeme over a number of years. I see her as a bit of a maverick, and I know she finds it difficult to conform to management decisions that she sees as inappropriate. She has, however, been instrumental in setting up a number of new services for people with dementia. It was obvious from the interview that we know each other, and in many ways have had the same views on a number of issues.

5.3.1 Being in practice

The overall story is about the practice of an experienced practitioner, the complexity and multiplicity of working as a community mental health nurse with people with dementia, and especially people who have dementia and hallucinations. She uses clinical stories to illustrate the sophistication of her work, and the skills she uses. Dementia becomes part of people's lives, as do hallucinations, but they are not the entirety of their lives, and it is possible to teach people to cope with aspects of it, but it takes time and skill in assessment.

She tells of the relationship she has with clients especially Graeme. There is a theme of the intensity of relationships in which both individuals work. The words 'people' and 'person' are repeated, distancing herself from suggestions of 'patient', and suggesting that she considers people as individuals, rather than as part of a homogenous group of people with dementia. She acknowledges that when there are more people involved, as in a staff group in a care home, a consistent therapeutic approach is more difficult to achieve.

There are tensions between her desire to be an individual, and the constraints of being subject to the demands of the larger organisation. Although she acknowledges that she is part of a service providing health care, there is also a refusal to be straightjacketed into the confines of the organisation.

when I have my first interview with people with dementia it's almost a non-clinical visit, if that makes sense to you, because I'm not there to fill in forms, I'm there trying to get to know the person, the official form-filling etc. comes in later

She is confident in her skills as a practitioner. She emphasises her 'creative' approach with people that is not part of her training or experience

Liz: You say that you take quite a creative approach – where does that come from?

Kim: That's me

There are a number of references to using herself as an individual.

I think it's probably because it's how I run my life and this is going to sound as though I'm quite prescriptive here but about what I do but I try and get people to look at everything that's going on in their life

'Work' is a word that is repeated throughout the interview, both in relation to herself, but also to the person with dementia. The relationship is not just social, but some sort of work is being done in her interactions with people.

The phrase 'you know' is repeated by Kim 32 times in the interview. Brown and Gilligan (1993) propose that repeated use of 'you know' suggests that the interviewee may be unsure that the interviewer shares that knowledge. Kim mainly uses this phrase when talking about specific interventions she makes with people with dementia who are referred to her. She uses it 14 times in her description of her work with Graeme; her knowledge here about him is based on her relationship with him, which is different to mine. I am an ex-colleague who has done the same job but perhaps I do things differently and at one point she distances herself from me

we are all individuals because you and I would do things differently to the same end point and probably reach the same end point but we would go about it in a slightly different way

5.3.2 **My response**

Kim is an experienced mental health nurse who has been working with older people with mental health problems, then specialising in dementia care for over 20 years. I know her fairly well, having done a similar job and worked collaboratively with her on a number of projects. We have a similar approach to many of the issues discussed during this interview. I recognise her sense of fascination and her enjoyment of discussions with Graeme, which I have also experienced.

Her story begins and follows a pattern I recognise. It is the work of an experienced practitioner, starting at the beginning of a referral, with an initial feeling of not knowing, leading on to an assessment process, the need to establish a relationship and then a treatment plan. This is the way that most nurses would set about working with someone.

I understand her sense of frustration at the system. I too have experienced having to balance the demands of the organisation with wanting to provide the best care to individuals, who do not always follow the prescribed route.

I was surprised that she did not discuss the shifting nature of hallucinations, which is my experience of hallucinations. She adopts the line of working through how real hallucinations are likely to be. She suggests that mostly hallucinations need attention from the nurse. I am not as convinced by this view, as I think they can sometimes be a harmless activity that can be a way people stimulate themselves, when they may be bored.

5.3.3 **Three voices: confidence, creativity and dissonance**

For this reading I made an I-poem, and then read the poem for the voices that I heard. I identified three voices in this way.

5.3.3.1 **Confidence**

The strongest voice coming through was the voice of a competent and confident nurse. Focusing on the voice of the 'I' in this interview shows a thoughtful practitioner. An I-poem constructed in a part of the interview describing her own

work with individual people in which she is confident and in control, uses the collaborative 'we' and verbs of action

The voice of confidence has few doubts about her practice. The uncertainty at the beginning when she uses 'I suppose' and 'I think' is not about her abilities, but about not yet knowing the person who has been referred. This voice tells what she does as a practitioner from referral, getting to know someone and building a relationship with them, to the work she engages in collaboratively with the person. She tells the story of this process with Graeme

Me trying to get a handle on

When I visited him

I knew

The conversations that we had

I knew that there was something

I couldn't always work it

Made me think

More than I was led to believe

The referral I'd had

Once I recognised

I was able to then start

I thought was

I actually had to work on em again

I had to revisit the diagnosis

We really

I would say cracked it

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That's what I mean
The work that we did
That's what I mean
We took a step back
We took each episode
We just really work through it
We talked about it a lot
We talked

This voice is empowered and reflective. She is confident in her knowledge and knows she can tell me things about her practice 'What else can I tell you?'

5.3.3.2 **Creativity**

Another voice is the voice of the creative individual. Although she is a mental health nurse, she is also an individual who may do things differently from her peers

We are all individuals
You and I would do things differently
We would go about it in a slightly different way

This is why she enjoys being a community mental health nurse; it enables her to work individually with the person with dementia.

When it's me and the patient
We've made our ground rules
We've got our contract
This is what we'll do
We'll change things

This contrasts with her thoughts about the difficulties for care homes in getting all members of staff to collaborate in a consistent approach

I think that makes it worse
I find most staff are prepared to try things
I think that's the starting point
I do think staff in care homes
I think that's one of the biggest challenges for staff
I do think
I find more so in care homes
I'm asking them to work in a particular way
That's what I mean

This voice also tells of her reasons for enjoying the job, her fascination with dementia and the brain which allows her to use her creativity in flexibly working with people

That's me
I find dementia
I find the brain fascinating
I think what happens
I don't think anything is clear cut
I'm just prepared to try anything
I never harm anyone
I do ask people

5.3.3.3 **Dissonance**

The third voice is a voice of dissonance, where the creative competent practitioner has to work within the confines of a system with which she does not always agree. She acknowledges the tensions, not to question her own values, but to find ways of subverting the demands of the system.

I'm not there to fill in forms

I'm there trying to get to know the person

She is not always prepared to fit in with the system but keeps what she is doing quiet

I'm not quite sure

How it goes down with my colleagues

5.3.4 **Working in relationships**

In the third reading I focussed on how Kim talked about relationships. The relationships she spoke about were predominantly with people with dementia, then with their families, colleagues and other people with whom she worked including staff in care homes.

She describes a collaborative relationship with the person with dementia, where both parties together achieve change. The word 'work' is repeated 58 times throughout this interview; the relationship is not a social one but a working relationship.

Initially the balance of work is tipped towards the professional as she has to work to try to clarify what is happening for that person

'but it's about really working out what it means to that person..then I would hope that I could work with the person'.

It is then the turn of the person with dementia to work with her, when she talks of Graeme she says

'I'd probably say out of all the people I've seen over the years Graeme probably worked the hardest and followed everything that I suggested'

She tries to identify the things that someone values as being the aspect of their life that they will both work on. She illustrates this through a model of 3 aspects of life

I try and get people to look at everything that's going on in their life and split things into three. There are things that you can do and they're not a problem and you can carry on doing them and there's no issue there, and there are things that you

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do that are becoming more difficult but quite frankly you don't need to do, and there are things in the middle that are important and are difficult and something needs to change in order for that to keep going. So you've got the first third which is not an issue at all the third third which are things you can actually do without and then you've got the things that are really important and that's what people often want to work on because they want to keep that part of their life going

It is not always easy to understand what is happening for the person with dementia especially if they are experiencing hallucinations. She achieves this by talking to them and getting to know something about their lives. Even then it may not be clear but may be something an experienced practitioner 'picks up'.

through the conversations I have with people it sometimes takes time before I can actually pick up that I think there is something which is not quite right because a lot of people if they had if the hallucinations have been a part of their life

Her main aim is to help people through transitions such as coming to terms with diagnosis and other changes in their lives. She also believes that people with dementia can adapt to change and cope with their life as someone with dementia for longer, although only in the earlier stages

you can help somebody to make changes in their lives and you can help people to recognise what's happening to them. I honestly do believe that they cope better and for longer but it has to be done as early as possible

Although people with dementia can be taught skills to help them adapt they are not able to carry these over into different situations, when another change happens this needs to be addressed again.

I tend to find with people with dementia if I can teach them one thing the difficulty is, because of the damage that is happening in their brain that those skills are not transferable to another situation so it's almost like you have to start again

She finds reciprocity in her work, she enjoys it because she finds the brain fascinating but in the case of Graeme she also finds their conversations fascinating despite sometimes being irrelevant to the issue at hand.

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we ended up talking about oh everything to do with politics and nothing to do with the issue at hand because the conversation was very stimulating. It was kind of hard for me to get back on track (laughs) you know. I went in there very focused and the conversation just became something completely different and I would go away and I would say at the end that's not what we started out to do but it was really interesting but we're going to have to do this again (laughter)

The people she sees are all different and live in diverse situations so she needs to have a flexible approach to her work. It may conflict with the expectation of the NHS that requires certain procedures. She links her style to her own creativity.

She often works with staff in care homes to try to achieve a difference for the individual residents. This is more of a challenge because she is not able to control the situation. In these situations she sees her role as trying to change culture through teaching. She is the dementia expert in these situations and is trying to help them to work in a certain way. She is removed from direct caring here and acknowledges that there are difficulties for a staff group that she as a lone practitioner does not face.

trying to get a consistent approach happening is difficult

It is also difficult for them to understand the differing realities of people with dementia who hallucinate as they care for too many people. It is not easy for them to adjust between individuals.

5.3.5 Working with dementia and hallucinations

Kim works within the mental health care system and when she talks of dementia it is as a collection of diseases that are diagnosed, and are progressive.

it's a whole mix of people that I would see, and covering the whole range of all of the dementias and all the age groups and all the stages that people go through

Dementia has a neuropathological cause

I find the brain fascinating and I think what happens to the brain when it develops dementia makes the brain even more fascinating

A diagnosis is important. She works with people immediately post diagnosis to give them information about the illness and to help them to come to terms with it. People like Graeme are diagnosed with or given the diagnosis of a specific type of dementia.

first of all he was diagnosed with dementia with Lewy-bodies

Being unsuccessful in reaching a diagnosis is a failure of the expected role of medicine and its contract with the patient.

this is 7-8 years em you know since his original diagnosis and of course in that time the diagnosis of Lewy-body hasn't isn't his diagnosis, so he also had to learn to come to terms with the fact that he didn't have that and he had something that we couldn't give a name to, which was very difficult

Hallucinations in dementia can be part of the disease and can evolve with the brain damage

something changes and that's usually as the dementia progresses and the hallucinations become distressing

There is a suggestion of a definite singular reality that is the 'common sense' view of reality and that may be different from the reality of dementia and hallucinations. People who hallucinate may, however, have 'merged them into their real life'.

People like Graeme may respond to a logical argument, they have the

ability to recognise for whatever reason that it something can't be real for instance somebody who sees 100 people in their back garden but if you actually measured out the back garden 100 people couldn't get in there

Although he was aware that 'strange things were happening' they 'were very real' to him. He distinguished between 'the realities of life and the reality of dementia'.

Although Kim uses a disease model to explain dementia, she is clear that people are individuals and will respond in different ways

it is very individual because it's different for everybody'

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Dementia is just a part of their life not its' entirety and her role is to enable people to maintain their lifestyle as far as possible

so that the dementia part of their life doesn't become too disruptive.

5.4 Summary

Care is shared in this case study; Lesley and Graeme are involved in the long term care relationship of father and daughter. Kim is involved in caring professionally for Graeme and also Lesley, with her recognition of the role of family carers.

Caregiving is complex and collaborative, based on relationships, reciprocity, professional knowledge, negotiation and resources. Graeme is responsive to care from both his daughter and his community nurse, responsibilities are negotiated and fluid.

There are slippery boundaries and uncertainty for Graeme and also for Lesley. Hallucinations and dementia can be unpredictable and they both have to navigate temporal slippages. Kim is more certain of hallucinations and dementia with her professional knowledge, uncertainty for her is the personal knowledge of the person with dementia which exists on first meeting them.

They all approach hallucinations as something that can be challenged, Kim has taught Graeme techniques for this, which he uses and he also asks for Lesley's knowledge and assistance when he struggles to find 'reality'.

Graeme was the first person I interviewed in this study and our contact led to my first conflicts in the field. The following section addresses some of the unexpected difficulties I encountered.

5.5 How to be a researcher: how do I know?

Attention to reflexivity has become an integral aspect of qualitative social research, it is expected that the researcher acknowledges their own position within the creation of knowledge (Mauthner and Doucet, 2003, Finlay, 2003). A voice-centred relational method of data analysis builds a reading for the researcher into the first reading. The interpersonal context of my research relationship with Graeme resulted in some unanticipated requirement for reflexivity in my study. I will begin by located myself in relationship to Graeme, and then discuss a specific incident within one of our interviews that caused me to question some previous assumptions.

5.5.1 Situating myself

I knew Graeme from the past and I felt comfortable with him, knowing some of his life history. Although this was my first research interview, my knowledge of his situation meant that I did not need to ask for clarification about his family, nor some of his hallucinations. I like him, we share similar political views and I was amused by his description of shouting at a political debate on the TV. I was, however, unsure of our research relationship, I did not know how to be a researcher but I did know how to be a nurse. He brought me his medication to show me how many tablets he was taking and talked to me about his community nurse and psychiatrist, acknowledging my relationship with both of them, and positioning me as a nurse.

He is a person with dementia and I do not currently have dementia, but I do have a lot of experience as a nurse working with people with dementia. I am conscious that I used skills acquired in clinical practice, in relating to him, such as allowing him time to tell his story. Listening to the recording I sound more Scottish with him, in a subconscious attempt to relate.

I do not share his hallucinations, but have a similar difficulty in knowing them; I see them as a slippery concept. His uncertainty about how he knows, mirrors mine, how do I know? He talks a lot about sleeping and I wonder if there is any connection with hallucinations. He has said he sometimes finds it difficult to distinguish between hallucinations and ‘reality’.

I see people in the hall ...there's probably naebody there and
I don't know if it's because I'm overtired

He reiterated that he is happy being alone and is not lonely but this confused me. I am certain that his world is shrinking as he restricts his social interactions mainly to his family. I was also concerned about his description of his experience of feeling inadequate at a group to which I had accompanied him in the past. I find this difficult to hear as it reflects on my previous experience of advocacy of this group. I am sad that things are becoming more difficult for him.

This sense of sadness is much stronger for me following the second interview when I found it overwhelming. It raised issues for me about my previous work, had this been of any value when dementia seemed to be such an awful experience with an inevitable decline. I also felt abusive, that I was just making him sad for the sake of my study. I wondered if I had become too removed from practice and now see it in a rosy glow. I remember feelings of sadness in practice.

I am obviously attached to Graeme, we have had a relationship over a number of years and I feel powerless that I cannot make his situation better. When I listen again to the interview I am very aware of my need to end it on a positive note and not leave him feeling bad.

Following the interview I discussed my experience in supervision, and my supervisor suggested that I should possibly look for a way of providing some sort of reciprocity to him. I suggested to him that we go out for lunch. He had told me about his difficulties in making meals and that it helped when his family took him out for lunch.

I wrote the following notes in the days following the interview.

5.5.2 Notes on emotional impact

‘Do we risk appearing foolish to our colleagues (and a lay audience) when we admit to naïveté, ignorance and /or uncertainty, that is when we let slip the cloak of authority that traditionally has set us apart from the people we study?’

(Hertz, 1997) pxvi

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I am a skilled mental health practitioner; I say this possibly to reassure myself. One of the courses I studied during my MSc was reflexivity. At the time I thought it was interesting enough but nothing new to me, if truth be told I thought it was a bit of navel gazing. Of course I am used to dealing with people's emotions and I know how to interview people with dementia; I have spent much of my career doing exactly this.

5.5.3 Extract from interview

Graeme I said a silly a really really silly thing to Lesley and Bridget (daughters). I said it'll maybe be better if I get to the stage where I don't know at all what's going on then it wouldnae bother me but because I know that silly things is going on. I'm doing I just I just cannae cope. It's just so frustrating, that's why I cancelled going to Berwick, because frighten's no the right word, fighten's no the right word it's concern that, and it's it's no other people it's myself. I'm no I'm no er because as I say most people are understanding and try and help but there's only a few people that I would trust and see I start to feel sorry for myself I mean, the now I'm feeling sad and sad's the word

Liz mhmm mhmm

Graeme sad's the word. I, it's no feeling sorry for myself I feel sad that it's come to this

Liz right

Graeme that I cannae go and do what I used to be able to do and I know, I know as we get older and things happen but I mean I'm no that old and I'm no

Liz yeah

Graeme it's just that my whole personality, personality and character has so totally changed I find it difficult to cope with

5.5.4 Extract from Field notes

I felt uncomfortable during much of the first part of my visit when he talked about his sadness. Partly I felt I may be making things worse for him by making him talk about it. People are often wary of this type of response when talking to people with mental health problems but I did not experience this while working as a community mental health nurse.

What is this about? Do I see myself as therapeutic as a nurse but not as a researcher? Do I worry about upsetting people for no good reason? Is this a reflection of how I value my study?

This feeling became more visceral for me in the days following the interview I started to feel almost abusive in the way I was using him. Why was I suddenly feeling like this? This experience brought me up sharply I was surprised and confused, I had paid lip service to reflexivity but suddenly I needed to re-visit it. What does this mean, being both subject and object of my study; I wondered how it would look. I spoke to other experienced mental health nurses who had done research degrees and discovered that they tell similar stories of trying to negotiate boundaries between being a researcher and a practitioner.

Liz Bondi (2005) argues that a range of emotions can be experienced in a research study from excitement and passion but those seen as negative are the ones which are problematised. Emotional responses are accepted as multiple and fluid until something occurs to upset feeling rules. I had accepted my upbeat feelings of relief and happiness that Graeme wanted to speak to me at all, to help in this study and worried that he may change his mind at any minute.

Graeme had said that there were only a small number of people with whom he feels safe, and had included me in that number. I fluctuated between feeling flattered that this was a reflection on my ability to establish a relationship with someone with dementia, and feeling slightly uncomfortable that I was using skills from practice in a dishonest way. As Jennifer Mason reminds us we can suddenly become too close to the experience of our research participants and ‘surely that is intrusive: a bit like stalking?’ (Mason, 2011: 15). The boundaries appeared to be blurred between myself as practitioner and researcher in an unexpected way.

Graeme’s expression of feeling in this interview could be viewed as very telling of his experience of living with dementia. It has proved to be useful data both within that context, but also as an illustrative narrative of a novice researcher. Birch and Miller (2000) both believed they had gathered ‘good data’ during their studies involving self-disclosure. Somehow these interviews had been more authentic and

revealing of the self. Each, however, experienced different reactions to the idea that the person they were interviewing found the encounter therapeutic. One of them found this to be uncomfortable, the other did not.

I come from a world in which the predominant research narrative is that of objective medical science, and it is easy to forget that respondents will situate the researcher as much as the researcher situates the respondents (Hertz, 1997). The way people define the identity of the researcher can become apparent in the way that they talk (Silverman, 2001). The way they attribute meanings to the researcher selves will affect the way they receive them. What did Graeme think about my role, despite knowing that I was doing research and was currently a student, he knew my background and knew me as a nurse before this research study. He almost certainly still identified me as a nurse, there had been times during our contact when he discussed his medication and he asked about whether I had seen his community nurse or consultant psychiatrist. Rheinharz (1997) identified over twenty selves when analysing her field notes which fitted into 3 main categories. We bring different selves with us into fieldwork and also create selves within research as research based and situationally created selves. Graeme knew the self I brought as nurse, colleague of Kim and also a friend of someone whose mother his wife knew. I bring or create in the field someone who listens.

Graeme I find it difficult trying to explain to people and there's only the likes of yourself or Kim or my family that I'd be comfortable talking about it

Extract from interview

Oakley (1981) in her seminal paper about interviewing women describes the idea of a 'proper interview' as a masculine paradigm. It aims to collect data from a passive interviewee, and emotions would get in the way of 'real science'. Although this chapter was written 30 years ago, the suggestion of objectifying the person being interviewed seems to be an idea worth considering in this instance. I know that my voice will be heard but how can I enable his voice to be heard too? Is this even possible when I will always be the person making the choices about what is heard.

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Should I be even trying to get this self-disclosing voice heard though, this is supposed to be research not a therapeutic interview. If I accept the voice-centred relational method of analysis, my emotional reaction has to be acknowledged as a source of knowledge (Mauthner and Doucet, 2003). I do not have a diagnosis of dementia, and have spent much of the last years of my career trying to challenge the belief of dementia as an illness that destroys people's identity, is that why I reacted so strongly to him expressing the idea that perhaps it would be better when, and if, he no longer realises what he is doing. Does this negative concept of dementia really reflect how I feel about it and thus negate my professional practice?

The issues in this encounter seem to be about me as a researcher and how the boundaries are being crossed with my nurse self. Emotional labour where work involves feelings has been identified in a number of occupations including nursing (Smith, 2008). I felt like I knew the feeling rules (Hochschild, 1983) as a practitioner but not the feeling rules needed to be a researcher. There has been a growing body of work on the sociology of emotions but the impact of emotions on the researcher remains an underwritten topic (Hubbard et al., 2001). There are a number of reasons suggested for this, including the continuing dominance of some aspects of positivism and the belief in objective science. Fieldworkers may be expected to utilise subjectivity to establish relationships, but emotion is suspect in science, so mixed messages about emotions abound in even qualitative research (Kleinman and Copp, 1993). Coming from a world of psychiatry, this remains a factor affecting my experience.

I found myself conflicted yet again, between the different roles of nurse and researcher. Should I have silenced Graeme to make me feel more comfortable? I do not think I did anything different from the way I would have reacted as a nurse; I allowed him to express his feelings and knew at the end of the interview he was no longer distressed. I also telephoned him the following day to make sure he was not upset. For Graeme there was a continuous questioning of reality; maybe I have to learn something from this analogy.

Clinical supervision at this point enabled me to engage with the ghosts that haunted me, behind what Doucet describes as the '*gossamer walls* through which researchers construct knowledge' (Doucet, 2008: 1). As I reread and listen to the interview I am still shocked when I reach the point at which he says it may be better when he reaches the time when he is oblivious. It challenges my belief in equity; I feel it is unfair that this decline is happening to him. I continue to wonder what this extract was about, the reflexive aspect of situating myself emotionally continues. Reflexivity is integral to the voice centred relational method of analysis but I was surprised by the strength of its impact on me in my second interview with Graeme.

Dave



Figure 4: Midsummer tree

Illustration R Middleton

6 Dave, Joan and Alex

6.1 Dave's realities: 'a hallucination is a sort of up market dream'

Dave lives with his wife on the fourth floor of a private block of flats. Their living room is a large room with a lot of natural light. It faces out to the front of the building onto large mature trees and a small building site. The kitchen at the back of the house overlooks a golf course that is separated from the grounds of the flats by more large trees and a high wall. Dave sits in an upright chair at the end of the living room where he can easily see out of the window. He has mobility difficulties and the chair is designed to make it easier for him to get up and down.

He was diagnosed with Parkinson's 20 years ago. I recognise the involuntary writhing movements of dyskinesia, which can be associated with Parkinson's. Because of the Parkinson's, his face can seem a little expressionless and I find it hard to read the emotional nuances, so initially I find myself surprised by sudden flashes of dry humour. His voice is very soft and tends to disappear, making it difficult to follow at times. There are a number of occasions when I have to tell him that I have not heard what he has said. He sometimes loses track of his story and at one point he says he has lost his place. He has been to courses run by speech therapists and learnt a number of tricks to aid communication. He knows that he needs to practice these skills and tells me that he notices the reaction of other people. If they are yawning he says he realises his voice is disappearing. I needed some time to tune in to the way he communicates. Despite these difficulties Dave is very keen to talk and to tell me about his experiences.

He has recently been diagnosed with dementia and according to the community mental health nurse who recruited him to my study; he has vivid hallucinations that he is happy to discuss. My interviews required a flexible approach. Mostly I spoke to Dave alone, but his wife returned towards the end of my two individual interviews and I interviewed her with Dave present on a further occasion. He has carers who visit to give him lunch on the days his wife goes out. The twice I visited coincided with the tail end of the carer's visit. When I was to interview him for the first time,

the carer had only just given him lunch; they had been late because they were tidying the garage. I did not record the first half of our conversation to give him chance to eat his lunch. This was a slow process and he in fact told me a lot about changes in his life during this period.

6.1.1 Extract from field notes of Interview 1

The door was opened by the paid carer who told me that Dave was having his lunch as they had been busy tidying up the garage. I went through to the living room and Dave joined me, the carer brought through his lunch. The consent form was lying on the table; his wife had completed the parts which did not need a signature. I discussed the consent process again and he said he wanted to go ahead. The carer came through to join us for lunch so we chatted generally. The carer asked about what I was doing and I explained. This led to a discussion of retirement and Dave said he couldn't imagine working full time again as somehow the day just disappeared. When he was a young man he used to be a 'night owl' and would often work from 10.30pm – 3 am as well as being at work. Now he found it difficult to finish the crossword and to read the paper.

I was aware of his need to finish his lunch so did not think I should start the interview, although he seemed to want to start telling me things. We tried out the recorder and this led to discussion of a course he had attended to enhance his speech because of the difficulties from his Parkinson's. He had found this helpful but intense, requiring practice like all skills 'not like riding a bike'. He has friends who will point out to him when his voice is becoming quieter. His conversation had started out quite positively, we discussed my studies. Then I asked him about his career as a teacher, which he obviously relished. He had also done other learning, such as a course in Hungarian.

He then spoke of the difficulties he experienced. He feels that his skills have been wasted for example he used to be good with his hands and had collected many tools over the years but now he cannot use them. He gave examples of difficulties in doing simple things like making a cup of tea, which he has done four times a day for years. He now ends up putting cold water in the cup or putting water in the coffee jar rather than the other way round and he becomes frustrated at being unable to correct this mistake. He knows it is wrong but can't work out how to fix it. Another example he gave

was of dropping a pea onto a shiny table and instead of picking it up with his fingers or a knife, spending a lot of time chasing it around the table with a fork, leaving a mess of sauce then realising that people were wondering what he was doing. He was disappointed that I had not recorded this conversation due to me waiting for him to finish his lunch

Dave tells me the story of what he sees. In the word cloud, 'see' is the most prominent word in the first interview. He starts by telling me that he has always been imaginative, then moves on to his perceptual difficulties, what he could see, and how to an extent his vision was corrected with glasses. What he sees then becomes more fanciful, he sees his family in the house and he sees people outside in the trees. He also shows me what he sees; taking me to the window to show me what is in the trees.

The other story he tells is one of difficulty in doing things he has previous taken for granted, such as calculations. This is a theme that is continued from before the recording, when he told me how he felt his skills were now wasted. He tells me how 'pissed off' he is with the consequences of not being able to distinguish what he sees, especially that he is no longer allowed to drive.

Parkinson's disease disrupted the expected path of his life but it was something he learnt to live with, the reality was not as bad as may have been anticipated. In the same way his dementia, which is a later diagnosis has not so far proved as difficult as the disease he may have dreaded, had someone previously told him he might get dementia. He distinguishes between the two at the beginning of the third interview and then is unable to separate them 'I'm having trouble separating the effects of Parkinson's and dementia'. I am struck by his use of terms such as 'not part of the masterplan' and 'my version of the illness'.

Although changes to his lifestyle have been necessitated, they have not been so difficult to cope with. He is not sure what the future with dementia will be like but having managed Parkinson's he seems optimistic that he is up to the challenge of dementia. The later part of the interview is about the distinctions between reality, hallucinations and dreaming. It can be difficult to separate dreaming and

hallucinations and imagination in the same way as it can be difficult separating Parkinson's and dementia, this is his version of the illness.

I am surprised by what I see as his playfulness with regard his hallucinations. I think they would fit DSM IV criteria as hallucinations but he relates them to creativity and imagination, which had not occurred to me. He seems playful in his approach to what he sees outside. His wife tells me he had described a full cricket match taking place in the trees; she asks him if this is still happening and he tells her that the cricket season has finished.

6.1.2 'My version of the illness'

He rejects the dominant understanding of his two diagnoses, that they are overwhelming and tragic 'there are some that thinks that would be bloody awful'.

His view is that

with the modern medicine available Parkinson's is lessened. I think and I'll wait 10 years if I last that long and tell you how the dementia has done.

His 'version of the illness' is the one that he and his wife cope with. Comparing himself to some other people he realises 'how badly off some other people were and that maybe we weren't so bad after all'.

This voice talks of both change and continuity. He compares his life in the past and now: 'I used to be' but 'now I get my mashed potato cut up' but he rejects being identified as the disease, and asserts his right to be an individual with the disease 'we had my version of the illness' and talking about an episode of hallucinations 'this is my experience'. Although both Parkinson's and dementia have affected him and restricted his life

My mind's not as sharp

I can't get the letters

and

I can't get my body to do

What I want it to do

He has an accepting voice about these changes and says 'I don't dwell on it'. He was able to express his agency throughout, was not overwhelmed by the unexpected onset of Parkinson's disease and is confident in his sense of self

I was able to carry on

we were offered early retirement

I was able to take

I wasn't earning any or significantly less

His desire is to continue as an autonomous actor making lifestyle choices

I'd rather know

What I'm going to do

I would rather choose

When I can say

Despite the changes which have been wrought on his lifestyle by illness 'we learnt I think to cope'. He is optimistic about the future, describing himself now, following prescription of anti-cholinesterase inhibitor medication as

I feel as if it's not that bad

I'm not so forgetful

I'm not so cack-handed

I I don't know

I mean

I'm getting dressed

It's easier to put my socks on

He compares himself with others and thinks he is managing equally well

I was at a lunch yesterday

I as far as I was aware

I was able to keep up

His view of his core nature remains unchanged ‘my nature in general is’ and ‘that’s my particular philosophy’.

He talks of himself as active in helping me with my study

If I'm not telling you

Tell me

I would rather tell you

Many of the verbs he uses are verbs of action, describing how he goes about doing things ‘my mind breaking down a problem’. Some of these strategies are no longer working for him

I was a little perturbed

I not read the clues

I couldn't answer them right

I I cannot do simple arithmetic

I have to pass it on to somebody

I can't even divide by two

Despite the changes he experiences, there is a strong sense of continuity in the way he talks about himself, things are explained with reference to himself in the past ‘I’ve always had a vivid imagination’ and ‘my mind is the type of mind’.

The ‘I’ who speaks sees things and illustrates this by telling what he sees, he also shows, he goes to look out at the trees where he often sees people in trees and points out what he is seeing. When I tell him I am unable to see what he describes he is unfazed by this

Dave: but I’m quite sure you can see

Liz: no I can’t see that

Dave: no?

6.1.3 The great masterplan

Dave and his wife had anticipated a different retirement to the one that was interrupted by Parkinson's disease. The vocal and politicised professionals of his generation, especially prior to the latest recession, expected a long and active retirement when they would be much fitter and more prosperous than previous generations.

He lives with his wife and talks about her in the relaxed manner of a long-standing relationship. He says of her 'she'll be on at me not eating my lunch again that she's spent hours slaving over a hot stove no it'll be my fault don't you worry'. This is a humorous reference to a relationship in which he is comfortable. He describes her reaction to him bringing in 4 cups of tea because he has seen other members of the family in the room 'Joan says what the hell have you made all that tea for?'

Dave regarded his relationships as positive although much of our interviews are about him as an individual. He starts our third interview talking about himself as part of a couple, their expectations for life when they retired that turned out differently to the reality

it's obviously not what we not part of the great masterplan..of
life when we were 20 odd you know what we thought would
happen..when we were coming up for retirement

Dave is less active in the joint interview but it was organised as an interview with Joan rather than a joint interview. He agrees and disagrees with her without any obvious difficulty. It is their relationship, that he predominantly dwells on and he reiterates that accord is important to him

I don't think that there's any what may be called disharmony
about it

I think there's to me it's an important aspect of it that there
could be arguments and quarrels

Although he says

I sometimes don't accept it in that I think she's wrong

A couple of seconds later he says

But I've accepted she can't see them and therefore they
probably are hallucinations

He has to struggle with the differing realities and finds himself in the position of capitulating. The harmony is important and maintains the relationship

You've always been supportive you know you've not always
seen my point of view as to what you may not agree with it.
You may not see and you don't and think I shouldn't see
whatever it is I see

His health is not something that affects only him; he allocates joint ownership to it. It is not just him who has his version of the illness but 'we had' it. He perceives an equity in their relationship despite his difficulties; they dealt with the reality of illness as a couple 'as far as it's concerned Joan and myself just dealt with it' and 'it doesn't cause disharmony between us'. His hallucinations do not cause dispute between them.

Other family relationships are discussed in the contexts of either hallucinations or dreams. His children feature in his hallucinations of people in the house; his daughter appearing regularly. He describes hallucinations of his son experienced during the night. The following day he apologized to the neighbours for the behaviour of his son and his friends

he tended to bring his friends around at 2 o'clock in the
morning all in their cars and all sitting in the neighbours'
drives because they'd got the wrong one and their usual
teenage carrying on

This fits with the predominant Western tradition of parents being responsible for children until adulthood but there is a disjuncture in his experience. His initial response as a father of teenage children was redundant as he recognises that 'I was thinking of him as back at school'.

It is members of the family like his daughters who he 'sees' in the living room, whereas outside he sees strangers. There is nothing strange or unusual about members of the family visiting, what is strange is that when he returns from the kitchen having made them cups of tea they have disappeared. His mother appears in a dream and reassures him by 'magicking' things which are disrupted back home.

He obviously has less day-to-day dealings with the organisation of his medical needs than Joan, and he talks of the medical profession in general, who become entangled in a hallucination. When he is awaiting discharge from hospital he thinks that

the nursing staff had put me in prison

Again there is a disjuncture between his hallucination and social expectations of nurses and he discovers that 'people were being sympathetic'.

Friends were discussed before the recording started, when he talked about his speech difficulties. He has friends who will point out to him that his voice is getting lower enabling him to correct this. He has obviously been involved in the resident's committee as he illustrated his difficulties in calculation now, with an illustration from an incident affecting the residents.

Friends and neighbours provide practical support

it also generated a lot of help from people, neighbours,
friends all made a little sometimes a big contribution to
making life easy..nothing major just little things in life; a bit
of baking something, or come down for your tea tonight, save
you cooking

6.1.4 External reality

Most people conceive of a single everyday external reality. Despite the dream like quality of his hallucinations Dave also uses common-sense logic to experiences in a way that to me does not seem to fit. An example is that I visited one very windy day and wondered if the movement of leaves and branches would affect what he saw.

When I asked him if this made any difference to his hallucinations of people in the trees, he adopted a matter of fact approach and told me 'it'd be a silly hallucination if a boy came out in this weather and started to climb trees'

For Dave there can be a distinction between 'reality' and what he experiences when

I discovered that in reality

I woke up

I was being kept in a nice comfortable bed

I was sitting

I hadn't been out

There is a dividing line between dreaming and reality here and 'I had transposed the dress from the hallucination to reality or reality to a hallucination' again suggesting a distinct divide.

He says 'I tend to see' but other people's reality can seem to be more reliable than his own and proof is difficult to find

I don't know

I don't

I would say

I can't give you any evidence

I'm not surprised

I suspect it is

I can't offer you any

He says that he has had to reject his own reality at times

Liz: and when I tell you that I can't see that do you think that it must be something that you're just seeing

Dave: I've come to accept that it is but it's very difficult because sometimes it's so real

The responses from other people can give him a clue that he is not experiencing the same things as them. He describes hearing music and asking the neighbours about it the next day 'funny looks all around'.

6.1.5 **Certainty**

Dave speaks with the certainty of experience

I still maintain

As far as I'm concerned

If I may come in

This can be with regard to whether he needs help

I don't need help

I don't need reassurance

I know

I can logically work out

It is also when he talks of perceptual experiences that he knows differ from those of Joan. In this extract she has asked him if he experiences hallucinations when he is staying at his brother's house

I will see

As far as I'm concerned

I went out to remonstrate

He describes ephemeral, intangible episodes often with a similar certainty

I'd define them as dreams

They don't worry me

If I waken up

They stay with me

I can remember

As the fact that he is no longer allowed to drive

Firmly entrenched in my mind

Strongly influenced my life

I can't drive

I mustn't drive

It annoys me

I just have to accept it

This voice of certainty can, however, let him down

I can distinguish

I will constantly speak to them

A blank back at me

Until I realised

He is not always certain

I'm disturbed sometimes

I can't remember now

I had to get on a train

I was left to take the fares

I won't argue

I've never established

This uncertain voice has difficulty in distinguishing between hallucination, dreaming and 'reality'

I got all sorts of complications

In my hallucinations

In my was it a dream

I cannot be absolutely sure

I'm dreaming

I don't know

He cannot trust himself, his reality fluctuates enough 'to make me wonder'. His experiences become uncertain and so he describes them as dreams

I have a dream
If I can describe it
I can't explain
I'm dreaming
I'm not able to distinguish
I don't know

This uncertainty can cause anxiety 'I was in a small panic' and so he found reassurance from his mother

I spoke to my mother
I did that
My mother appears
My mother said to me
I put away the slightly disturbing imaging

He describes the difficulty he can have in 'separating as I said reality and imagination' and 'I cannot be absolutely sure whether I'm dreaming or hallucinating'. 'It's a bit of a mixture' and he explains a hallucination as 'a sort of upmarket dream'.

He associated his hallucinations very much with his imagination, telling me

I have always been able to I suppose think laterally and create situations I enjoyed acting

in response to me asking him to tell me about his hallucinations. He then goes on to justify this

I think it's necessary to say this first because I know some people don't have that capacity.

It is only recently that these things have been renamed hallucinations, since he became involved with the Community Mental Health Team

I'm trying to think about my first impressions of what are now called hallucinations

Previously they may have been related to his ability to 'given any situation I can make up a story'.

The way he describes his hallucinations reminds me of the way I have thought about my dreams and how difficult it can be to tell them. I know the feeling of trying to tell something so ephemeral that slips away as you try to grapple with it. I am surprised by his slippery boundaries between dreams and hallucinations as I have assumed they are very different concepts.

He ended up telling me about dreams. I was not sure if he thought that his dreams were hallucinations and he said he was not sure of the difference. I wonder at the experience of reality for him and Graeme of dreams and hallucinations being closely connected. Somehow this topic has to do with the boundaries being blurred and liminal spaces.

6.2 Joan's realities: 'just part of our lives'

Joan is Dave's wife. She asked me whether I wanted Dave to be present during our interview. I told her it was up to them and they decided he would stay, with the option to leave the room or fall asleep if he felt bored. In fact after a short time Joan was including him in the discussion about his experiences and it became a three way conversation. She had said that she was happy to say anything in front of him and is very matter of fact about his experiences, having no difficulty in disagreeing with him about what he sees.

In this joint interview I hear how both Joan and Dave, two people in a long term relationship have adapted to integrate hallucinations into their life together. As Joan says 'I mean they're just part of our lives'; they are not a major disruption to their day to day lives.

In the interview Joan switches between talking to me about Dave in the third person and talking to him in the second person

But obviously Dave sees them no matter what I say.
Sometimes you seem to see things for a long spell

She explains something to me, and then includes him for clarification.

When listening to Dave and Joan together, Joan starts by telling of her uncertainty; she is uncertain about what he experiences, but she is certain that it is different to her 'reality'. Dave enters with a 'but', despite her uncertainty he has the certainty of experience. As she says 'I don't know' he says 'I still maintain' and having been ignored as she returns to uncertainty he comes in a second time more assertively with

As far as I'm concerned

If I may come in

They agree the uncertainty of an episode in hospital when he became acutely confused

Joan: I can only remember

I think that's really

Dave: I had 3 or 4 days

I just wasn't aware

They both agree that hospital admissions cause disruption and she concurs with his description of his post discharge experiences as

it was nightmares it definitely it was real nightmares and you just did not know where you were and then you just speaking a load of rubbish most of the time and that was at least I think a week after

She uses popular imagery of madness when describing his behaviour in hospital

You were completely bonkers then weren't you? Absolutely round the twist absolutely round the twist for 3 days

This was a different degree of reality disjuncture to seeing horsemen on the golf course.

6.2.1 Mediation

Joan acts as a mediator for Dave with me, ensuring I can hear him by reminding him that his voice tends to get softer 'you need to speak up Dave' and reminding him to stick to the point

You don't know that Dave anyway that's nothing to do with hallucinations

She also uses her knowledge and experience of an event to clarify. Dave told us of a hallucination whilst staying at his brother's house. Joan has not heard him tell this previously so is making this clearer for both my benefit, and her own satisfaction

Joan: And this happens when you're sitting where, in his lounge or in the bedroom?

Dave: in er the sunroom

Joan: looking out at the sea?

She helps him when she is aware that he is unsure of what she is saying

you've always said that you've hallucinated more since you went on to the what are the combined Sinemet and whatever the other one was em what's it called Entacapone since you started taking the red one

In this extract there is no pause and no verbal clues that Dave is not sure of which tablet Joan is talking about, but Joan's personal knowledge of Dave allows her to assist him without him needing to ask her.

Personal knowledge and humour is demonstrated as part of this long standing relationship in their discourse. Joan checks with him about his experiences, and a sense of humour is evident from both of them. She also helps me to understand by clarifying with him. She reminds him of the medication he now has, 'that's the one that Alex (community nurse) gave you the memory one the small patch'.

Joan knows, and reminds Dave of the chronology of events in their lives together. She also provides reassurance and a reality check for Dave

I don't turn round and tell him he's a silly old fool and there's nothing there

I'll just say where is it you see them and I'll say no Dave there's nothing there. It's a man playing golf it's not a horse. I mean quite often he will call me through you know if I'm in a different room

She also mediates with health services. She describes telephoning to organise hospital appointments, and then how a previous hospital experience had been so disruptive to him that she had to tell healthcare staff how to care for him

yes because the he had another foot operation about 4 or 5 years ago and for some reason they kept him in the day bed area and that was really bad because all he could see all the time was people walking around with masks and gowns and you were completely bonkers then weren't you absolutely round the twist absolutely round the twist for 3 days until I really let loose and I said you have to get him back into a ward you know and actually they got you you got 1 of the wee rooms and within 6 or 8 hours he was compos mentis again he knew where he was he knew what was happening you know and I thought so last time he went in I said to

(name of surgeon) he has to go to the ward and they were
very good you got a single room again

This empowered voice that has individual knowledge of Dave, and is active and assertive in fighting for what he needs when he is in hospital is easier to identify in the I-poem of this extract. With this voice Joan acts as his advocate to ensure that he is receiving better care

I phoned up
I must've phoned
I really let loose
I said you have to
I thought
I said to Dr

This voice is informed by her personal knowledge of her husband and her day-to-day experience of living with him.

6.2.2 **Knower**

She has intimate knowledge of Dave as husband, father and grandfather. There is obvious humour in their interactions built of a long-standing relationship. Although she is joking she uses a stereotype of someone who is mad by saying

I don't think he's ever going to er turn around with an axe
and try and get rid of me

The hallucinations are part of the family life even the grandchildren are involved in responding to them

They now accept that Dave will see things that they know are
not true and they the older ones will actually say to you won't
they?

This family knowledge of his hallucinations help Dave to distinguish between the reality of seeing people on horseback across the golf course, and the consensus

reality of other members of the family, and so the grandchildren care for their grandfather when Joan is out shopping

We came back and the first thing he (grandson) said to me was 'it's alright I looked after grandpa. I told him there weren't any children jumping off the balcony'

Hallucinations are so much a part of family life that family members are often included in the hallucinations. When Dave has hallucinations of people in the house it is family members he sees.

There is a tension between what is consensus reality and Dave's reality. Joan uses common sense reasoning to try to deal with this

I obviously don't agree with him I try to say how can children possibly be up those trees? They couldn't climb up the trees, try and try and reason and bring sense into it

6.2.3 **Not knowing**

In the second reading I hear the voice of uncertainty as she repeats 'I don't know' eleven times

I don't know

I mean

I just have to say

I mean

I don't know why

I don't know

It is a puzzle that will not be solved 'not in our lifetime'. This is the voice of the individual with different perceptual experiences, who finds it difficult to make sense of hallucinations. She repeats 'I mean' during this interview, which suggests to me that a normally articulate woman is having difficulty in making sense of what her husband is now experiencing.

She tries not to negate his reality but is clear that she will not collude in it ‘I obviously don’t agree’ and

I’ll just say

I’ll say no Dave

She does not always know that he is hallucinating, there are no outward signs and she relies on him to tell her

He doesn’t always tell me when he hallucinates

Another way of her knowing, is when he acts on them, for example making tea for family members he sees in the living room, or he asking her to look at something to see if what he sees is actually there.

She does not know, as she cannot imagine what he experiences. Dave’s experience of reality is unimaginable

No way I can picture

If I close my eyes

I still can’t picture

I often I wonder

I’m sure it won’t make any difference

She cannot understand how he remembers a hallucination and describes it so vividly

How can you remember all this Dave it’s nearly a year since.....you can remember that clearly.....you can’t remember things that happened yesterday but you can remember hallucinations?

The words ‘dream’ and ‘hallucination’ are both prominent in a word cloud of the interview but in separate word clouds for each of them Joan uses ‘hallucination’ more and Dave uses ‘dream’ more. Dave finds the boundary between dreams and hallucinations more confusing, it is difficult to name the experience so he settles for the term ‘dream’, which both Joan and I may understand ‘let’s call it a dream just now’ and ‘let’s stick to the dream if I can define it as falling asleep at night’.

She disputes his view that his hallucinations are part of a spectrum with dreams

So they're dreams maybe rather than hallucinations?

But she sees a possible association between him sleeping and hallucinations

and I don't know whether you see more when you first
woken up because you've been thinking about it or dreaming
about it I don't know

A dream is 'just' a dream; it is commonplace and something we all do whereas
hallucinations are different. They are more exotic.

Waking and dreaming may however have a fuzzy boundary and become a liminal
space in which hallucinations occur

I don't know whether you see more when you first woken up
because you've been thinking about it or dreaming about it I
don't know

She looks for explanations and excuses his mistakes, when he tells me of difficulty in
finding his room during the night she says 'it's only in the last 9 months or so we've
swapped rooms' so despite us discussing how he sometimes transposes one flat for
another he is rescued by blaming his memory.

She looks for the explanation in organic changes in the brain

They're very strange...it's not as if you can say that part of
the brain's got a blockage or something that's causing it

For both of them there is a difficulty in knowing what a hallucination is. Joan is
clear that dreaming is different. She looks for reasons for this to be happening, one
of which is the psychiatric term 'hallucination'. This word is used throughout the
interview but sometimes Dave's experience may not fit what she sees as the
definitive classification. When Dave thinks he has to collect their daughter

that's not really a hallucination I don't know what that would
come under you know what that would be be classed as

Later on she says

I think the only thing that sometimes worries me about the hallucinations is and hopefully it'll not go down that route is if Dave really does think he has to go and collect one of the children and he physically goes and gets the keys when he's not allowed to drive. He's not insured that worries me

This may not be a hallucination but in terms of her anxiety it becomes a hallucination.

Drugs may be the cause

you've always said that you hallucinated more since you went on to the what are the combined Sinemet

Or drugs may be the answer; he has recently started taking one of the Anticholinesterase Inhibitors

Do you think it's actually helped with the hallucinations? I think it's helped with the memory

She knows but she does not know.

Near the end of the interview I am struck by Joan saying

maybe sometimes it's better to have hallucinations than think about things that are actually happening

This seems to be the only time that there is a suggestion of sadness about the changes that Parkinson's disease has made on their lives. It appears to contrast with the matter of fact way that the rest of the discussion has been about the hallucinations just being part of their lives. Difficulties are minimised as they become just part of life but the phrase 'maybe sometimes it's better to have hallucinations than think about things that are actually happening' perhaps tells of a less than easy relationship with his difficulties.

6.3 Alex's realities: 'I can think of a chap'

I interviewed Alex, Dave's community nurse in his office. When he suggested that Dave might be willing to participate in the study, he told me that he had a long history of Parkinson's and now as far as Alex was concerned Dave had dementia with Lewy Bodies. This is a source of dissent between himself and the geriatrician who thinks that the diagnosis of Parkinson's is adequate.

Alex is an experienced mental health nurse who knows me well. He speaks to me as a fellow professional who understands the nuances of people with dementia and hallucinations. I too am a mental health nurse with many years' experience and I understand and identify with the way he tells stories of individual patients to elucidate his thoughts. It is the way I have chosen to write this research study. This illustrates the issue of the insider position in my research.

6.3.1 Story teller

Alex understands dementia as a medical problem with a history, 'you'd know from clinical records'. It is progressive, has stages 'the sort of stage of dementia that people are at' and a symptomatology. So

the sort of stage of dementia that people are at and how do
they articulate what they're experiencing varies and so
somebody who had a history of, had maybe visual
hallucinations or olfactory hallucinations as their disease
progresses

He uses clinical cases to tell stories of the distinction between biological knowledge and individual expression of illness. Cases illustrate and make disease process interesting, they are used throughout medicine. He uses direct speech to dramatize his stories as in his description of a lady who sees schoolboys visiting her. Alex repeats 'they were cheeky young lads' bringing the scene to life and drawing the listener, me, into the story. He is a competent and entertaining story teller. He positions himself as a medical professional in his use of case illustrations

I remember another chap

I pleaded and won my case

I haven't seen that again

I asked him about it

You couldn't treat with anti-psychotics

This is a story of the heroic nurse who fights for the patient to be prescribed Donepezil in spite of rationing, and is proved right. It is one of a number of examples he uses to tell of his experience. Although he admits this is a one-off experience, there is certainty in this extract. When he tries to recall in general, he changes from the first person 'I' to the second person 'you' ; the generalised other. My interpretation of this shift is that this is something shared. I too am a mental health nurse who may be unsure.

I couldn't actually give you a number

You can guess

You can maybe guess

You know

You'd know

You can only second guess

You can guess

I suppose for me

His knowledge is gleaned through cases; he illustrates through people he has known rather than abstractly and he also thinks that way. He searches to remember people he has seen in care homes when I ask him whether people hallucinating is something that causes problems in care

I can't remember

I have

One may pop into my head

Give me long enough

I might think

I'm thinking

I have visited

I can't think

He uses illustrations of people he has known with other difficulties and wonders if the way staff think of them is transferrable to hallucinations.

6.3.2 The Expert

He positions himself as an expert, a detective and an educator. He is a detective with people with dementia; it is not always obvious that someone is hallucinating. A community mental health nurse needs to 'unpick' what is happening, based on 'observation yes of how somebody behaves' but

the issue is if it affects them functionally; how they are within themselves if they're scared or angry. If it's something that's comforting then that's kind of nice.

Hallucinations are often associated with an increase in other symptoms associated with dementia

it was definitely a symptom of things getting worse. The more intense they got it was clearly correlated between what she was functioning and managing independently and how em and how her symptoms of dementia were becoming more apparent; her disorientation, her short term memory, her affect, symptoms of recall and cognition were clearly correlated to the intensity and the nastiness of the experience and it was kind of I don't know which comes first but this they certainly come they are certainly related

Here cognitive decline is placed centre-stage (Hughes, 2011).

Dementia does not only affect the person who has dementia but also positions relatives as carers 'they will often have family carers'. He sees his role as an expert and an educator with carers. This is the way to help carers

so often a bit of carer education in terms of looking at how the person with dementia feels and how they interpret that

Other care professionals like GPs and care home staff can do the wrong thing

I remember the GP saying to her “don’t be stupid there’s nobody in your attic” which didn’t really help but in as much as it became quite confrontational

Care home staff can use the jargon ‘hallucinations’ wrongly and do not have the expert detection skills of mental health staff

I’ve seen staff interpret it as that when it’s clearly not been to me that that’s the case. Oh they might say ‘they’re saying they’re doing this or that’ and I’ll say ‘yeah but they’ve also got a rip roaring chest infection and they have a delirium so we know people experience this kind of thing with delirium but we have to treat the delirium and then we’ll see what’s left’. Lo and behold they are no longer experiencing or describing things

He sees himself as fighting against the value judgments of society as manifested by care home staff whose assumptions about sexuality in older people may get in the way of catering for their needs.

the behaviour is more than acceptable it’s in the interpretation of the behaviour I digress but an overt expression of sexuality there’s actually nothing wrong it’s more down to your own set of values about how older people express their sexuality

6.3.3 Complexities

The stories he tells often concern the complexities of living with hallucinations. Hallucinations are not a static phenomenon, which would be easier because enjoyable hallucinations should be left alone. He tells the story of a man who sees ‘little dogs that ran around the house’ that were a source of pleasure for him

he would then chuckle away and laugh at the antics of the little dogs however it became a problem when the little dogs were getting into the bed at night while his wife was in bed and he was inadvertently whacking her

He describes a textbook definition of different sensory examples of hallucinations but we know it may be different. When describing hallucinations in general a textbook definition will have to suffice but a particular person can deviate from this.

Despite his definition of hallucinations, when he talks to me a fellow community mental health nurse he is less positive about their boundaries

I've seen people who have I'm never sure if they're
hallucinating or not or but they are misinterpreting or rather
superimposing incidents from the past that are very vivid

Here there is less clarity and definiteness, hallucinations do not have to fit into the textbook definition. The definition is vulnerable, it is not necessarily set.

GPs and care home staff misuse the term hallucinations, but when he is talking to me about hallucinations, it is clear the term may not be clear cut. Hallucination is however a psychiatric category and as a fellow mental health nurse I can understand the nuances.

I agree with him about the difficulty in deciding what is, and is not, a hallucination. I have always found this a slippery concept in my practice, and I am not always sure what is a misperception, or memory, or hallucination. It is my experience that they can slide over the boundaries, often without me being aware of the changes. The way he uses the diagnostic term hallucinations inclusively with me as a fellow professional, validated my decision to include the term in my recruitment criteria as I was fairly sure that we would share a similar understanding. Probably if I was a researcher from a different background the data generated would have been different. We jointly construct the category of hallucinations and dementia.

6.3.4 Dilemmas

Although there can be an assumption that medicine is objective, clinical medicine is not value free. He describes how quality of life is affected by both dementia and by side-effects of medication and a medical professional struggles to assess where the best position lies. It seems to be a decision of medical professionals though, rather than an inclusive discussion with all involved.

Alex talks of the everyday dilemmas of clinical practice; these are often dilemmas which are shared by the clinical team he identifies with

You couldn't treat with anti-psychotics

We'd knock him for six
Do we make him stiff
Do we let him experience those

And

How do you manage that
It's you know
How do you modify that
You know
Do you like reassure her
That's the approach we took

The dilemma voice asks questions and mainly uses 'we' instead of 'I'. These are the dilemmas that are faced by mental health professionals with people who hallucinate. They are not a dilemma when someone is not distressed

Why would I want to treat with something
You take away a source of pleasure

We don't always know, and it is impossible to know what someone responds to in the later stages of dementia, one can only make a guess based on observation of behaviour and previous history.

6.4 Summary

Dave and Joan situate the hallucinations in the context of a relationship, from Joan's comments about them being a part of their lives to Dave's checking with her when he is unsure of the reality of something he sees. All three of these participants have a view that hallucinations are not necessarily a negative experience; they may provide entertainment in a situation in which there is a lack of alternative stimulation. For Dave hallucinations can be entertaining and for Alex too they can provide an entertaining story for fellow colleagues.

Hallucinations are not meaningless and lacking in context as in diagnostic categories but are situated within a narrative life.

There is doubt and certainty within all their stories, knowledge is never clear-cut and the boundaries are ambiguous.

Simon



Figure 5: Wee man

Illustration Simon

7 Simon, Jeanette and Alison

The interviews with Simon and Jeanette differed from the previous cases. They were interviewed together on two occasions and so I have chosen to analyse and write them together.

7.1 Simon and Jeanette: the sort of thing I would probably incorporate into a drawing

Simon lives with his wife Jeanette in a spacious modern flat. He was my final participant and I was extremely relieved when he was suggested as a recruit by his community nurse. I had been struggling to reach my target of three cases. He has only recently been diagnosed with dementia. He and his wife have an active social life and often spend time in their other house which is in a rural area some distance away.

7.1.1 Extract from field notes

These field notes were written after my first meeting

He answers the door and explains that his wife is on the phone. He shows me into the living room, there are three copies of the health education booklet 'Coping with dementia' lying around the room. I assume this means that he is aware of his diagnosis but wonder why he has got three separate copies. Do people just send them or give them out automatically without checking and what does it mean to have them prominently on view? We chat generally while waiting for his wife. When she arrives I explain the purpose of my study. Simon points out that he has had only two episodes of hallucinations when he was in their other house in the country. I ask if he remembers them and he says yes in fact he has drawn them. I am excited by this as I am interested in visual representations of hallucinations. I check what they call the experiences and they both say hallucinations. Simon asks about my academic history as if checking my credibility.

As I am about to leave, Simon says he thought medication was involved as he remembers Alison the community nurse mentioned a placebo. I am convinced that Alison understands the study and would not have mentioned a placebo, his wife tells him this was not the case and I was

fairly certain I had been clear in my discussion. My heart sinks as I think he will not see my research as useful and will not wish to participate. I leave my leaflet and arrange to telephone them in a few days to give them time to discuss it and decide whether they want to participate. I feel pessimistic, convinced that they will refuse.

I telephoned them a few days later as arranged, and was surprised that they say they will participate. This made me more vigilant about process consent throughout my contact. We arranged an appointment in 2 weeks as they are busy socially and Jeanette told me they are trying to maintain their social life. I wondered if they are feeling that medicine and a diagnosis of dementia are beginning to take over their lives.

Simon and Jeanette decided that they wanted to be interviewed together and so I conducted two joint interviews. In some ways I found these interviews more difficult than those with Dave and Graeme.

7.1.2 Co-construction as creative imagination

Simon and Jeanette co-construct his experiences of hallucinations and dementia. They either minimize the experience ‘but you can see things in almost everything you look at’ or account for it as a feature of his special artistic gift.

Simon tells the story of his hallucinations as part of his artistic imagination. They are associated with the ‘loosening’ of his artistic style, so providing continuity with his previous self. He knows they were not real but

you know when you’re sitting down to draw a fantastic scene? ..It’s the sort of thing that I would probably incorporate into a drawing like that but I never was under any illusion that they were actually for real

They are attributed to his imagination and a source of artistic inspiration, like ‘a sort of scene from a pantomime sort of thing’.

Jeanette also resists the societal discourse of hallucinations as abnormal; utilising rather the discourse of the creative inspiration to explain them. It is an extension of

something he always had; not a problem but an augmented sensitivity to visual stimuli

you've been drawing and painting all your life but this is different. I find it difficult to put my finger on what it is but it seems as though you know from clouds and trees and buildings just what you're looking at it just seems to be heightened and you're also very easily distracted by the you know any visual thing, but it is, I mean it's not an hallucination it is actually what's out there

I was interested in how they both especially Jeanette, saw these experiences as something fascinating and a result of heightened visual perception that contributed to his artistic experiences. This had never occurred to me before. I found the fact that he had drawn the hallucinations fascinating as I am interested in visual representations. Is this like the driven artist? His hallucination of a hare on a motorbike especially caught my imagination.

Simon rejects the pathologising of his hallucinations when he says

but you can see things in almost everything you look at

so hallucinations are not something that reflect a mental health problem, but are the result of imagination. His hallucinations fluctuate 'it's like shooting stars and things rather than stories that's in colour'. He associates them with a change of consciousness like dreams that happen during the day

they're not really dreams in the sense that they happen at night when you're sleeping

although this then becomes fuzzy and 'I'm not sure about that now'. The boundaries begin to get blurred.

7.1.3 Medical science

Simon positions me as a health care professional 'I'd just been interviewed by er one of your colleagues'. He uses medical terminology to seek information 'do you get cases where it does disturb people?' Jeanette sees hallucinations as something that

when associated with other symptoms, is a medical problem that needs to be taken to a general practitioner

you'd had a lot of difficulty and I think it was because of the hallucination on top of that that we thought we'd better you know and so it was just seen by the GP as part of you know need to be referred back to the psychiatrist

Both Simon and Jeanette look for an explanation from science, and especially the pathology of the brain. Jeanette asks

Do they know why people with Lewy bodies have hallucinations what the mechanism is?

And 'is it some sort of disturbance in the visual area'. Simon uses a more visual metaphorical example to try to understand the workings of the brain

is it is the brain is it a bit like the starfish on the coral sea between Australia and New Guinea where you see all these black starfish came along erm and wrapped themselves around every bit coral and destroyed the whole coast

Although they try to normalise the experiences, 'it's not something we tell other people though is it'. Jeanette questions 'but is it that we feel it may put other people off'? In this exchange the implications of his diagnosis on others is made clear

Jeanette: the nature of your diagnosis really disturbs some people

Simon: oh yes some of the family er extended family sort of; yesterday my condition is not mentioned by anyone when I was there anyway

Simon is cognisant that having a diagnosis of dementia can result in any behaviour being blamed on the dementia

Simon: but er but just with (our) condition or my condition you just blame it on to

Jeanette: the dementia

Simon: the dementia whereas it's probably nothing to do with dementia it's just that you're annoyed

7.1.4 Hallucinations become a problem

At the time of first seeing his hallucinations, Simon accepts them, it is only later that he starts to think they may be strange. They only become something else when a health care professional shows an interest in them. A section of Simon's 'I' poem starts off in the passive voice

I was first being interviewed
I mentioned
Something which amazed me
I didn't think
I said to the person
Interviewing me
I suddenly became aware
I went more or less past him
As far as I was concerned
I think
I was out in the garden
I went out
I can't remember precisely
I was walking
I suddenly became apparent

Initially, although they were something that captivated him, they were benign and did not have any further significance. Someone else decided that they were of interest to the medical profession and he started to lose control of them. The initial use of the passive voice hides the focus from the performer who is an unnamed doctor. This happens again as he starts off with certainty

I thought it was quite amusing
I thought I was just dreaming

But I

I would probably incorporate into a drawing

I never was under any illusion

I was looking at

I found it amusing

I told people about it

I was leaving the interview

Asked me

It was something amusing that he as an active agent could use in a creative way, until someone disagrees with him and he has to rethink. When he talks about his diagnosis of dementia, it is easier when he has less control. He expresses doubts that he should feel this way

I mean that's one of the strange things about this whole thing is that for most of the time since I first became aware of it I've felt very happy. I feel that I shouldn't, it'll maybe change

Instead of his experience being denied by the medical profession, in this case it is Simon who resists it. The word 'dementia' is never specifically used in our first interview, although it is implied. Simon recognizes that despite his diagnosis he is feeling content. That he feels this is wrong, acknowledges the societal discourse of dementia as a deteriorating illness.

Jeanette views Simon's increased visual acuity as balancing the other problems

as opposed to you know the difficulties you're having the things that you're not able to do as well as you used to be able to do

Although it is something to do with his heightened visual perception about which

I feel

We can have a little discussion

They can only have a little discussion as there is still the larger question of his other difficulties

I didn't feel panicky

I just

We had already been dealing with

So I did know

We were aware

I did know

We had to go and see the doctor

They are aware as a couple that Simon's experiences may not be acceptable to others. They use 'We' to start discussing this

It's not something we tell other people

We haven't

Although Simon says he would not mind discussing it with friends they have not done this. He is aware that their larger family group silence such conversation

My condition is not mentioned

When I was there anyway

Such discussions are left to medical consultations where they are legitimate

that was why we went to the GP, because, but it was also because of the other things you were getting quite confused with, and you had a fall because we were at (place name) and the week in (place name) you'd had a lot of difficulty, and I think it was because of the hallucination on top of that that we thought we'd better you know and so it was just seen by the GP as part of you know need to be referred back to the psychiatrist

It is only towards the end of the first interview that Jeanette is able to acknowledge that she can be negatively affected

I hadn't appreciated

When we went to

And for me

I didn't know

I was experiencing this anxiety

They are however able to cope with this

So long as we don't have too many challenges

This is a different voice from the voice which minimalizes and finds it fascinating

We have found it interesting

Haven't we

Simon is less inclined to acknowledge the impact of his dementia on Jeanette, than she is; on one of the occasions he does, he returns to the impact on himself

well like yesterday we had ups and downs and ups and downs
all day long so I was exhausted at the end of it

In this section he normalises it

the difficulty is knowing whether it's due to just normal
living and having fights about something or other that every
partnership probably succumbs to from time to time

Jeanette however directs him back to his fluctuating functioning

I wasn't thinking about that so much but I think there are
days when you're struggling more than others that's what we
were talking about

Simon is the person who is experiencing the dementia and hallucinations and so
although for Jeanette it is something they can observe and discuss together

we have found it interesting haven't we the you know not just
the hallucinations but your dementia in some ways isn't it

She is aware that it has the main impact on him

how it's affecting you you know the observation of that that
sometimes sometimes you're OK with some of the things
then you're not you know and then you're OK again isn't it

7.1.5 Living in relationships

This is a joint interview and so is seen within the long standing joint history of a relationship. There are stories that are known to both, that can be seen as family stories. Towards the end of the second interview Simon tells a story of himself as a young boy

my first crossing swords with authority was when I was a
wee boy about 4 or 5 and my mother sent me.

This is obviously a frequently told anecdote as Jeanette joins in with 'it was your fare' and she uses it humorously to sustain enduring aspects of his identity 'and so it carried on your whole life'.

Simon talks of himself mainly as an independent, autonomous self in relationship to his hallucinations which are private and internal. He uses his life with Jeanette to check out the temporality and site of events. Jeanette provides cues for Simon such as 'can you remember it Simon?' and

you said to me you were passing a on the street where there
was a display of fruit....and there was a face on the apple

Jeanette talks of herself much more in relation to Simon, as evidenced in her use of 'we' throughout much of the interview. She uses the inclusive 'we' frequently in the interview to describe the private we of herself and Simon. Simon uses it only three times, once to include his 'cat' hallucination, once to include all of us in the room and once for himself and Jeanette, when he echoed her

We enjoyed

We were laughing about it.

The effect of dementia within an already existing relationship means both have to adjust to the impact. Despite finding the hallucinations interesting, she also sees them as difficulties that are associated with 'the falls and there was a lot of things

happening... and you were quite mixed up with other things'. She then keeps track of medical appointments

he had already seen Dr (name) and had a memory test in the February and she had she said that you had mild cognitive impairment at that point so we were aware that there were problems.

She slips effortlessly between addressing me and including Simon in the discussion by her change from 'he' to 'you'.

She positions herself as a helper for both Simon and me, with a puzzle to be solved

looking at what you struggle with and then it's like a puzzle trying to find something that will make it easier for you to do it. I think that's something that it's quite interesting in some ways to you know his experience of it isn't it you know the reading because you can read but you get very tired and things at night reading and er you know you were getting frustrated because you couldn't finish a book and you're dipping in and out and that but you know with the audiobook

She switches in this extract between 'he' and 'you' including both me and Simon.

She also assists me, earlier on when I have not understood Simon's attempt to try to get to grips with the physiology of the brain by using an analogy of a starfish.

She gives him cues to correct his sequencing of events. When he gets lost with telling me where the first hallucination occurred she assists him. She tries to orientate him without disempowering him. She attempts this a couple of times, telling him she was there, then she describes where they were. Her voice can be seen as one of rescuer but she is in danger of silencing him, she says

I remember you telling me

I don't think I was there

I can't think

She knows she was not there but chooses to appear as if she is unsure. This does not work as he repeats

You weren't with me

I don't remember

In another instance she explains in more detail what has happened.

We were lying in our bed

We've got Velux windows

You were telling me

Did I see the little man?

Jeanette too was slightly hesitant using 'I think', 'you know' and 'quite' as if not totally committing to her story.

They acknowledge that his anxiety can affect them both

Jeanette: you're quite kind of anxious and I hadn't appreciated how much until you start you know.... you were much more relaxed that it was much better for you that whole thing wasn't it

Simon: and for you

Jeanette: and for me (laughs) I didn't know that I was experiencing this anxiety at second hand

She quickly silences her own needs as an individual and returns to his needs

you did the same thing when you were on the motorway because you're quite anxious about it now aren't you so these things help don't they

And then them both as a couple

so long as we don't have too many challenges in one day

At only one point in the second interview she silences him

Jeanette: I think maybe because Simon was doing so much art that you know

Simon: I'm genuinely trying to explain to you what

Jeanette: yes but I think you're very aware of the visual thing anyway and I would say that in the last year that you have a heightened visual perception

7.1.6 Parity

Although they are co-constructing their account, they do not always manage to maintain equity in their account. The second interview began with Jeanette telling me that Simon had had a further hallucination. This interview starts out with some confusion on the part of Simon about the experience mentioned by Jeanette prior to me recording. Jeanette has defined the topic of the conversation initially. He is disadvantaged by not recalling the incident and she provides cues which he is eventually able to follow evidenced by their repetition of 'I think'. Jeanette's words are in italics in this section

No I can't

You said to me

I think

I think

I mean I've

Both employ a voice of uncertainty throughout the interview using 'I think'. He manages to regain control of the conversation when he says with certainty

I've you know

I wakened

I've told you

I've not seen a thing

I mean

I just get into my bed

I put the light off, I'm out

At another point in the interview, Jeanette has started with

We have found it interesting

Haven't we

Her attempts to promote parity are rejected. Simon silences her joint ownership of dementia with

We had ups and downs

So I was exhausted

I've discovered

Why I was getting so er getting confused

I was putting where it says

She tries to direct the conversation again with

I wasn't thinking about that

I think that there are days

But he silences her again with

The other thing that's got worse is em my ability

I mean

7.2 Bringing a community nurse and researcher together

Following the first interview Simon had said he wanted to know what I was writing about him

7.2.1 Extract from field-notes (2nd interview)

Simon had asked to see what I was writing about him so we agreed initially that he look at the transcript of the last interview. I had sent it to them a few days previously. They thought the transcript was accurate and Simon that said nothing further had happened since my last visit. His wife then said that he had had a further hallucination so I asked if I could record the conversation

On reflection I wonder if I was just paying lip service to his desire to read what I wrote about him. I do not think that I had worked out what I would do if he did not like something I had written. Perhaps I was being disingenuous to his request; I assumed he wanted to read a transcript rather than to read my interpretation of the interviews, which is a different story from the one he tells me.

7.2.2 Talking about dementia

I found myself less at ease with Simon than my previous two participants. I felt at one point in particular I was floundering to know whether to mention the word 'dementia'. On my first visit to discuss the study, I was aware that three copies of the health promotion booklet 'Coping with dementia' were lying around the room. Although critical of this oversupply, I assumed this meant that he had been given a diagnosis and was comfortable with that. When he says

I mean that's one of the strange things about this whole thing is that for most of the time since I first became aware of it I've felt very happy I feel that I shouldn't it'll maybe change

I again assume he is talking about his diagnosis of dementia and ask how long it is

since you got any sort of a since you went to see the doctor

I suddenly pull myself up from mentioning dementia, which gets me into more trouble

Simon: since I went to see the doctor about what?

Liz: about (0.2).you must've seen the doctor to talk about the em strange thing that happened

It is left to his wife to rescue me although she does not mention dementia either. She rescues both of us as we skirt around the 'dementia' label

Jeanette: We were in

Simon: Did I go and see Dr (name)?

I don't remember

Jeanette: We went to see the doctor

When we came back

I think we realised

In the following interview I found myself in the position of answering questions from them both about dementia and hallucinations. I was not sure if I should be answering them, but I had the information they wanted, and on balance it seemed to me that it was ridiculous to pretend otherwise.

Again I struggled with my insider/ outsider roles, during the data collection period this was a complex relationship for me, presenting challenges throughout the study. I have little doubt that being a nurse affected the interviews, but I was not always ready for the challenges that were thrown at me during interviews, a more experienced researcher would have faced some of these situations previously and would not have found them so unexpected.

7.3 Alison: I find it all very interesting

7.3.1 Extract from field notes

Alison is the community mental health nurse for Simon and Jeanette. Before this interview she had participated in a focus group for professionals which I had run. She had been on sick leave when this interview took place but had suggested that she was interviewed during this time at her home. She met me at the train station prior to the interview and had asked me about how my research was going and a few questions about how Simon was as we walked to her house. She appeared interested in the research and as she had not seen Simon for some time she was also interested in how he was doing. This conversation resembled a colleague to colleague exchange. It was also in the informal setting of her home with her dogs interrupting as opposed to an office, which made it more relaxed.

We have both been employed to do the same work. I relate to her enthusiasm, and fascination with hallucinations, and her experiences as a mental health nurse. I also identify with her strategy of checking out physical causes of behaviour first with people who may hallucinate. This was how I would practise in clinical settings. She looks for a reason, as I am doing with this study. She tells a story of how a mental health practitioner works with people with dementia and hallucinations and makes sense of their experience. Her role as a mental health nurse is complex and she needs to utilise a number of skills, including establishing relationships, and analysing a situation to make sense of the reasons for behaviour

it was kind of picking that apart what made her think that that was happening

Alison is a thoughtful practitioner who sees her work with people as an on-going challenge

he wasn't sure if it was a visual thing and I kind of thought maybe I should know a bit more about visual things

7.3.2 Detective work

Alison talks of what Atkinson (1981) calls detective work, having to 'pick things apart'. To help someone a nurse needs to try to understand

It was trying to find out from her you know time of day. Was it dusk, was there particular lights? You know speaking to the daughter about what kind of street lights because obviously it's during the day when I'm there. What sort of street lights come through the window? And trying to pick that apart

When she is unsure about explanations for experiences of hallucinations, she thinks there should be an answer 'I should know a bit more about visual things'. She speculates on possible reasons for differing reactions to hallucinations 'Do you think it's something to do with em the level of intelligence people have?'

She looks for other explanations for the distress that some people experience, it may be to do with education, control or insight

He's aware that they're hallucinations

She has a personal responsibility to learn more to be a more effective practitioner

I wasn't sure

I kind of thought

I should know

7.3.3 **The man I looked after**

She discusses the case of Simon and his hallucinations and makes sense of his experiences by comparing him with other people.

he's quite animated when he talks about them he seems to find them quite stimulating, interesting and that's like somebody else I had involved with in the past they found them very, they enjoy talking about them

They are 'the gentleman I looked after' and 'a woman who was in a care home'. She is an active participant, when in relationship with people with dementia and has a specific role as someone who is there to help.

She is a well-trained competent nurse who values spending time with and listening to individual patients

I think I told you

The most interesting case I've had

I sat with her

I could kind of speak to her

Alison describes the importance of establishing good relationships with people.

the other guy that was really fearful of it was so real to him he wasn't able to see that it was a hallucination and there was only a couple of us in the ward that he trusted enough to say could you come and look at this and we'd say it's not there and he would accept it whereas if we weren't on, it would be very difficult for him and he would often act out on things em so that's a big part of it it's understanding that it is isn't real.

This can also be satisfying for the nurse

I felt quite privileged I suppose that he had that sort of relationship with me that I could say to him no there's nothing there and that would work

The most important relationships to Alison during this interview are the ones with people with dementia, and within her role as a community nurse; these appear to be fairly exclusive, with carers identified as sources of information. She describes previous relationships, working in a hospital ward where she expected staff to follow care plans and spend time with patients.

the staff didn't know how to cope with it and they continually medicated him when I had said you don't need to you just need to explain it to him but they had continually gone back and they had so many PRN²s it was never PRNs when I was on

This was the man with whom she felt privileged having a good relationship.

The relationships that are memorable are often those with a bizarre presentation

² P.RN: pro re nata. Term applied to medication that means it is administered as necessary, at the discretion of the nurse.

the most interesting one I've had was a woman..... and I'd never seen that before and it was horrible things like your parents have died and it was very unpleasant things that she was finding distressing

They are also the people who you are unable to help who haunt you

it's when you see people really distressed and you can't do anything about it

Relationships with people are important, and when knowledge is uncertain and you are unable to effect change, this is when she is most reflective

I don't know

Patients that you really remember

You can't quite

In your own head

You can't quite make sense

The ones you think about

You haven't

I suppose

In this passage she uses 'you' instead of 'I', this may be because she is positioning me as a fellow professional and including me in this uncertain knowledge, or that she thinks I perceive myself as a fellow practitioner. It is often the memorable patients who are discussed by professionals in clinical conversations. She slips into using 'you' not 'I' on a number of occasions when she is talking of uncertain knowledge. Mostly though her uses of 'you' are when she talks of the practical realities of clinical work, when the voice is a certain competent practitioner

The other one I had

You know

You know

If you sat and talked to her

You know

When you sat down

You know

7.3.4 **We like to sort things out. Don't we?**

Alison values knowledge, learning is important to her

When I'm there

I'd advised her

I think that's something

I should know more about

'Interesting' is repeated 19 times during this interview suggesting that she finds the work stimulating, meaning enthusiasm for learning comes naturally

I find it all very interesting I find it quite fascinating actually
how the brain works in that way

Her fascination motivated her to do more training

Actually inspired me to go on

And do my psychi

After doing my general

I do I do

I think Lewy Body is really interesting

Listening for the voice of 'I', the researcher should hear the sense of self of the participant. The main voice I hear in this interview is that of a reflective practitioner who is grappling with the uncertainty of knowing the experience of someone else and what it means to hallucinate.

I mean

I tried to rationale

I think

I don't know

I remember

I don't think

And another man I was involved with

We went up

I'd told his wife

She acknowledges that knowledge can be uncertain

I think

You know

How do you work out?

You know

You know

She tries to imagine the experience of hallucinating, which is difficult but then compares it to a personal experience of hallucinating when she was unwell.

I don't know I mean

I have when I've been really unwell

I saw the Grim Reaper

I was too physically unwell

She is quick to resist this, however, by reiterating that she was too physically unwell, distancing herself from people who have a psychiatric diagnosis.

7.3.5 **Specialist practitioner**

Despite her uncertainty and reflection she positions herself as a specialist practitioner in relationships with care homes. She expresses her disapproval of their use of medication, by questioning them about how long it took to work. She then 'proves' to them that medication does not work instantly, and therefore this was not the cause

of a change in someone. Her values about using medication inappropriately are evident in this interlude

The woman's that frail

She looks for reasons for care home staff practice and identifies their workload

staff are all too busy doing care tasks to actually find that sort of time

but there is also a conflict between her specialist skills and their views

because there was a bit of a kind of feeling from the staff that she didn't need it

so the person with dementia continues to be distressed

when I go to the staff they go really she's never said anything and I thought well it's just because they don't ask you know what I mean they don't get into the kind of how are you how are you feeling and then she would just come out with this stuff that was always very distressing

Although she has the specialist knowledge it is the staff at the care home who have the power to decide the care.

7.3.6 Diagnosis as a slippery concept

The contextual background to this interview and to both our work is psychiatry, which includes diagnosis, reality and normality, but in practice these concepts are more fluid than this would suggest. Alison uses the principles of biomedical knowledge to think about hallucinations. She uses diagnostic criteria, although they are not mentioned specifically

they were considering kind of re changing her diagnosis but it's really hard to pick apart the visual stuff so I think that's something I should know more about. I think you know is I, when does it, how do you work out the difference with something like that because of her sight? Is it what's the name of that syndrome Charles Bonnet you know is it that or is it you know more to do with the dementia?

She challenges the use of the specificity of diagnostic criteria

say sometimes working out is it an actual hallucination or is it a delusion or an illusion and sometimes being able to actually pinpoint what it is. Sometimes it's very clear cut and sometimes it's not

She describes the variety of hallucinations, from those she defines as common, for example seeing children and animals, and believing that family pictures have come to life

Cats and dogs are quite common things for people to see isn't it? Children, the other one

that happens quite a lot doesn't it people in pictures come to life?

Talking to family pictures is abnormal, unless someone is in the immediate stages of bereavement. There is also at the other extreme the very unusual

she said that she could actually see the letters it wasn't somebody telling her she was reading the words as she says they're there and I'd never seen that before

People with psychosis are often fascinating and bizarre to those of us who do not have these experiences, and Alison admits that she finds it all interesting. She uses the term 'bizarre' seven times, and at one point talks of an experience as

It's quite eerie I think because you know I remember visiting him he was in a care home and he said there's a little boy standing behind you it was quite eerie

This suggests altered states, ghosts and dreams, which to me become slippery concepts. Immediately following this passage she mentions her own experience of hallucinating 'The Grim Reaper' during a period of physical illness.

It is not just clinicians who are fascinated by these experiences but other people

he came to one of our dementia group and told everybody in the group and none of them had any experience of hallucinations and he told them in great detail about the people that were living in his house and they were fascinated by them

She challenges the assumption that hallucinations are negative experiences, as in her clinical experience this is not always the case. Negativity might however be anticipated

It's funny that people see them as maybe not as a positive I think that's maybe a bit strong as a positive but maybe as an interesting thing and they kind of make them more stimulated in a positive way

Liz: Yes I know exactly what you mean

Alison: Which is not what you'd expect

For some people she thinks they may serve a different purpose

it's seen as a very negative thing but actually the people I've had dealings with find them interesting and stimulating

The positive and negative aspects to hallucinations can change

And that's what changed for that other gentlemen that was in the care home was that because they didn't go away in the ways that when he tried to make them go away that he started to believe that they were real

Discrepancies with these realities are dealt with by discriminating between frightening hallucinations, and those that may be seen in a more positive light.

I've looked after people on the ward where their hallucinations were horrible and were a very negative thing

And

they kind of make them more stimulated in a positive way

She feels a responsibility to act, when they are causing people distress, but not when they are benign

I suppose when they're not distressing I don't worry about them too much it's when you see people really distressed

The professional will intervene in the perceptions that cause distress or a negative experience.

Yes to sort out these things that were difficult or just to have the reassurance that it wasn't happening

It is the professional who has the power and the voice in these encounters. It is not always easy to work out what is happening; perhaps the person with dementia can be powerful through silence

I'm sure with some people that you've interviewed that I've interviewed that haven't been totally honest about it because they're maybe not quite sure

Alison uses a common-sense reality despite the evidence that it does not always fit with the differing realities of the people with dementia she sees. Psychiatry often uses a scientific approach and she talks about having to 'pick things apart' to understand them. She looks for causes such as damage to the brain using diagnostic terminology like Lewy Body dementia. This is not however visible and hallucinations are not always associated with functioning

at that point he was functioning really well there was nothing to suspect he was managing his money going out to the shops driving his room was full of terrorists

Although hallucinations have slippery boundaries, diagnosis is a specialist function, belonging to someone with specialist psychiatric knowledge, nurses in care homes are not competent to diagnose

a lady in a care home who was convinced her husband was still he had died and she was convinced that he had come back again and he was having it away with a woman in the bay next door who was a nun and had 10 children and there was every time you went there was the staff would say you know she's not having any hallucinations

7.4 Summary

Simon and Jeanette co-constructed the narratives in these interviews and contextualised Simon's hallucinations within his identity as a creative person. A medical explanation was secondary to their understanding of the experiences but it was enacted as the reality of hallucinations within the medical setting of a medical interview.

For Alison, Simon's hallucinations are of interest, not a problem to him . She deals with a multiplicity of hallucinations and they are interesting to her too. She positions herself as a specialist practitioner who enjoys making sense of symptoms in order to alleviate distress.

8 Stories of hallucinations

Stories have to *repair* the damage that the illness has done to the ill person's sense of where she (sic) is in life

(Frank, 1997: 53 Italics in original)

In the previous three chapters I examined the individual stories of my participants, as triadic cases. In this chapter I draw together case study findings to demonstrate the centrality of narratives in understandings of hallucinations. The expansion of the interest in narrative inquiry in health and illness has contributed to understanding the complexity of not only illness narratives, but also to the way narrative is used throughout medical practice (Hydén and Brockmeier, 2008). This study contributes to this understanding by adding hallucinations and dementia. Hallucinations are woven into stories, demonstrating contextualised understandings. These challenge the decontextualized meaning that exists within psychiatric definitions of hallucinations. Demonstrating the contextual explanations of hallucinations focuses on the multiplicity of realities of hallucinations in practice.

The first section reviews the use of narrative within illness research and begins to address how my participants used narratives within this study.

8.1 Using stories

All the participants in my study used stories to talk about hallucinations, the stories that they told were multiple. Hydén (1997) distinguishes three uses of narrative that are commonly identifiable in research about illness, in social science.

- Illness as narrative – illness is expressed through narrative
- Narrative about illness- narrative is used to convey knowledge and ideas of illness
- Narrative as illness- a person is unable to narrate because of illness

The first use was evident in the discussion of hallucinations and dementia by my participants with dementia and their carers. They used narratives to integrate hallucinations and dementia into their lives and to create a new social reality.

Although people with dementia may fall into the third category, the people in my study were able to narrate their illness experience, albeit sometimes encountering difficulties. I found with Hydén (2013) that they were ‘creative problem-solvers’ and were often assisted by carers when difficulties arose. The narratives of professionals fell into the second category; they used narratives to discuss their knowledge and ideas about illness.

8.1.1 **Order**

Stories are a way of knowing, they are used to create order; events are selected and put into a sequence. Storytelling constructs a coherent linear whole from nonlinear temporal reality. Although all my participants had differing understandings of hallucinations and dementia, their stories were comprehensible and sequenced.

8.1.2 **Context**

Stories are used to create a context for illness. Nurses are used to telling stories about their patients; it is a daily part of their job. Alex started a number of stories with ‘I can think of a chap’. Normal uncomplicated cases are written up and forgotten, it is the complex stories where variations and anomalies abound that are remembered and re-recounted. Hunter (1992) writes about the stories of doctors, and nurses are no different in this respect, they tell stories to other colleagues. It is a means of conveying experiential knowledge in medical settings and can be used as a way of establishing the narrative identity of the storyteller. Kim tells the story of her ‘creative’ methods establishing both herself and the person with dementia as an individual

If their life needs to be improved in any way that’s what I’m
there to help them do and that’s why it is very individual
because it’s different for everybody

Although the initial focus of interviews with the professionals in my case studies was the specific person with dementia, I also asked them in general about how they managed hallucinations. They would inevitably start to tell stories of other individual people they had known, to illustrate hallucinations. Narratives about

illness are ways in which medical staff convey ideas and knowledge about illness (Hydén, 1997).

Clinical stories from my past were instrumental in my desire to undertake this research; I can clearly recall people with whom I have had a clinical relationship who puzzled me.

As Alison says

it's these types of patients that you really remember isn't it
the ones that are just something that you can't quite in your
own head you can't quite make sense of the ones you think
about a lot what was that about

Stories illustrate mismatches between knowledge of disease and knowledge of illness. As Hunter (1992) points out unsurprising events are minimally recorded, it is where there is an anomaly that it is worth telling.

Unlike in other types of nursing, performance for mental health nurses mainly involves talking and observing, there are no physical examinations involved. Asking people what they think, results in them interpreting realities, asking them and observing what they do results in performing realities (Mol, 2002). The nurses' use of specific cases to illustrate their points could be seen as them doing their own ethnography.

Although the 'anecdote' is disparaged in this day of evidence based medicine, Hunter (1992) argues that it has an often unrecognised place in the transmission of knowledge. Stories of individual patients serve as a reminder that clinical care is about the particular person's experience of disease.

Nurses mediate and negotiate with a complex network of others who may all have different expectations. Social aspects of living with an illness are added in to make a singularity. Various realities are added up and a treatment decision made in a specific context. Kim talks about

if it's me that can do it that's fine or if it's somebody else but often includes other members of the family or friends or places they go

8.1.3 Stories as creation of self

The work of people like Somers (1994) changed the focus of understanding of identity from a fixed essentialist explanation to a storied interpretation. She explains narrative as the method we use to know and understand our world. This results in a narrative identity in which stories can shift with time, and it is embedded within relationships. Narratives are the means by which people construct their identities within particular social settings (Holstein and Gubrium, 2000). Narratives have a role in sustaining identity and people have a creative capacity to maintain continuity (Richardson, 1997), they may also use disruptions to describe a change in life course (Hydén and Öruly, 2009).

Nurses used stories to create a professional self in my study. Their stories created them as competent and specialised practitioners, distinguishing them from other less knowledgeable nurses. One of the nurses told of a care home where staff did not recognise that someone was hallucinating because they did not take the time to listen to them. The mental health nurse has discarded the reality of the care home staff. They even felt competent to challenge doctors

but staff often use terms like hallucinating or saying that they're delusional or that they're psychotic you hear these terms used and GPs will sometimes use these terms when it's clear that that's not the case but people are just genuinely anxious or worried about something

Standards may conflict with the practice of the individual nurse. Kim tells me that she may be unconventional in her method of seeing people

I tend when I have my first interview with people with dementia it's almost a non-clinical visit if that makes sense to you because I'm not there to fill in forms I'm there trying to get to know the person the official form-filling etc comes in later

Stories were used by my participants to order events and create context for them. They were also used to create narrative selves, professional selves for the nurses and often continuing selves for people with dementia and their carers. Continuing selves were maintained by integrating hallucinations into their sense of self as the next section discusses.

8.2 Normalising hallucinations

Bury's (1982) concept of biographical disruption suggests that one of the ways people cope with chronic illness is to integrate it into their lives in order to achieve a sense of coherence of identity. My participants with dementia and their carers often used this narrative continuity to understand hallucinations. Sometimes they were integrated into their past identity, explaining them through their previous understandings and sometimes they worked hard to integrate them.

8.2.1 Hallucinations as continuity

Dave and Simon located hallucinations in continuations of aspects of their self. They both understood their experiences of hallucinations within important attributes of their narrative history. Dave's hallucinations are an extension of his imaginative capacity

I've always had a vivid imagination I have always been able
to I suppose think laterally and create situations I enjoyed

Dave

Simon has been creative and enjoys painting and so for him, hallucinations are a source of inspiration for his creativity. He used the experience as something to be drawn. This is demonstrated in his illustration of one of his hallucinations (Figure 5).

Simon and Dave both described these aspects of hallucinations, as did their partners. For Simon they were a continuation and a flourishing of his artistic creativity, and a source of inspiration. Both he and his wife described the loosening of his artistic style and their interest in the visions that he saw. Hallucinations are normalized within his artistic talent. Dave's descriptions of plays in trees were equally

imaginative. His hallucinations had started as an entertainment, he tells me of his first hallucinations, which were musical hallucinations that he could control, changing the genre at will. There is 'a little coterie of comfortable hallucinations' but he also has had less comfortable hallucinations.

Graeme incorporated some hallucinations within the context of his life now. The cat just sat in the living room. When I asked if he approached it he told me he had no need to because it sat there doing nothing.

8.2.2 Memories

Everyone was agreed that hallucinations had some meaning within the context of a life. People with dementia in this study engage with their hallucinations rather than understanding them as an external experience. For Simon and Dave this is a positive interaction. Graeme negotiates the reality of many of his hallucinations. When his hallucinations appeared to feel incongruous, he worked to re-interpret them. Both his community nurse Kim and his daughter Lesley helped in this work. He uses linear time through his life course to work out whether something is a hallucination. On one occasion he saw two girls sitting in his living room playing a game. He eventually worked out that this must be a hallucination, because they were girls he knew from the past, and they were appearing as much younger than they would actually be now.

Carers may be able to locate hallucinations in past experiences of people with dementia. Community nurses often locate hallucinations within a life course. Professionals identified past events as contributing to present hallucinations. These may be innocuous like someone going through the motions of fishing or more frightening as one nurse described

this lady had actually been a prisoner of war so she'd had a really horrific early years and one of the things that she used to get really distressed by, she lived at the top of a hill and lights, car headlights at night, used to come up the hill into her housing estate and she thought it was searchlights

8.2.3 Hallucinations as dreams

People with dementia often associated hallucinations with dreaming and spoke of the difficulty in differentiating between dreaming and hallucinations. Dave described his hallucinations as ‘an upmarket dream’. Graeme and his daughter Lesley associated hallucinations with tiredness and sleep, Graeme says

sometimes I I think I’m maybe half dreaming but I am
awake but I’ve maybe been sleeping

Although Simon seemed fairly clear that his hallucinations occurred within a wakeful period, he too mentioned dreaming

the main difference is that em they’re not really dreams in
the sense that they happen at night when you’re sleeping

As a researcher I was struck when listening to the accounts of hallucinations by the way that participants discussed the hallucinations. It resembled trying to tell dreams when they slip out of grasp during the telling. This is discussed further in the next chapter.

Dave’s ‘hallucinations’ became a ‘vivid imagination’ and ‘dreams’, he says ‘I’m not able to distinguish between hallucination and dream’.

Hallucinations were not totally understood as part of a narrative continuity, nurses and carers as well as some of the people with dementia integrated an understanding of hallucinations as part of a disease process alongside other understandings.

8.3 Hallucinations as symptom

Separating the symptom of hallucinations, from the disease of dementia was impossible in the study. Hallucinations are currently understood within psychiatry as a symptom of a disease. In the context of this study they were identified by me as an experience that could happen in dementia. All the nurses in the study associated hallucinations with a disease model of dementia, this could have been expected, as they were recruited as specialist nurses who worked within mental health and the inclusion criteria specified people with dementia, who hallucinated.

8.3.1 Hallucinations placed on a disease trajectory

Sometimes nurses placed hallucinations along a disease trajectory. Despite my perception that two of the people with dementia in the study had early diagnoses, nurses associated the appearance of hallucinations with a decrease in functioning, anticipating an inverse relationship

usually as the dementia progresses and the hallucinations become distressing

It becomes less easy to tell though, as the person in the later stages of dementia may be unable to voice their experiences and you have to guess by observation.

They are surprised when there is a discrepancy between the severity of dementia and hallucinations

at that point he was functioning really well there was nothing to suspect

8.3.2 Hallucinations as disturbance in brain

The increasing availability of neuroimaging techniques and understanding of neuropathology has meant that the causes of dementia and hallucinations can be increasingly placed in the brain. Some of the nurses described the aetiology of hallucinations as located in the brain. The relationship between whatever was going on in the brain, acted on the person causing them to hallucinate

I think what happens to the brain when it develops dementia makes the brain even more fascinating

The changes in the brain and the symptoms that they see in individuals add together to produce hallucinations related to dementia. The changes in the brain are of interest to the nurses, but for their day to day contact with patients, they are associated with a number of other factors to cause hallucinations in individual patients

so I find it all very interesting I find it quite fascinating actually how the brain works in that way and what it must be like for people

This medical understanding of dementia, as caused by pathological changes in the brain was powerful, extending to the carers and the people with dementia in the study.

Medical terminology was used by Graeme he used the term 'visuo-spatial difficulties' to explain. Frank would call this decision to tell a story in medical terms an 'act of narrative surrender' (Frank, 1997: 6). Lesley too looks for medical explanations. She places the cause of Graeme's difficulties in the brain although she is less certain in this knowledge than the professionals. She acknowledges the medical terminology and the expert knowledge of medicine.

he seems to internalise it it's like his brain and as I say this is
maybe the science the brain sort of can't work it outbut I
don't know what the animal hallucinations are all about

In this world of medicine the doctors are the people with the most valued knowledge, although nurses too have some of this specialised knowledge. The brain of the person with dementia is the object of knowledge and science is the method of knowing. This was the argument put forward by Foucault in his study 'The birth of the clinic' (1973): that the body became object to the medical gaze.

8.3.3 Diagnosis

Experiences of the disease label were varied. Simon had a recent diagnosis of dementia and says since he became aware of his diagnosis he has felt happy although perhaps he should not

that's one of the strange things about this whole thing is that
for most of the time since I first became aware of it I've felt
very happy I feel that I shouldn't it'll maybe change

Graeme places his hallucinations within the context of dementia and he and his daughter both struggle with uncertainty. The problem of diagnosing dementia has been discussed earlier in this thesis. Dementia is an umbrella term; it is a syndrome comprising a number of different diseases. The difficulty with this is that although it suggests discrete categories of separate diseases, they are not certain (Hughes, 2011). It has however become good practice to give people with dementia a diagnosis, it a

measure of quality within the Scottish government's dementia strategy (Scottish Government, 2010).

Graeme's identity has been disrupted by a change in medical diagnosis. He has had a diagnosis of dementia for a number of years and it has been more woven into his identity than for either of the other two participants whose diagnoses of dementia are more recent. A diagnosis provides an explanatory framework that makes sense of symptoms (Bracken and Thomas, 2005).

In his work on biographical reconstruction, Bury (1982) shows the importance of medical knowledge at a time of re-thinking biography in response to disruption. Medical discourse provides a possible explanatory framework (Schneider, 2007). Graeme actively uses a medical discourse as it explains some of the things that are happening to him and is a preferable account to the alternative, that he is doing these things deliberately. His hallucinations, although they are vivid, are not the most salient aspects of his experience of living with dementia. He struggles when the more specific diagnosis of Lewy body dementia is taken away, and is keen to confirm that he does have something

they don't think that I've got what they thought I had at the beginning but there's something going on and they can't put their finger on it.... they definitely think that there's something going on

A disease requires a redefinition of past, present and future in disease terms (Schneider, 2007). Graeme's hope for a future time of forgetting is a medical discourse that constructs dementia as deterioration into cognitive oblivion. Disease has become a 'scientific' explanation for Graeme in the face of meaninglessness, but the certainty that he seeks through scientific explanations is contributing to his uncertainty.

Simon and Dave are playful with the hegemony of professional authority in their reactions to being told they are experiencing hallucinations. They acknowledge the medical terminology but find it amusing. Someone else named their experiences

‘hallucinations’. Simon describes the moment at the end of an appointment with a doctor when his hallucinations become a medical concern

I found it amusing and I told people about it and laughed it was only as I was leaving the interview and that this Dr jumped on it and asked me a wee bit more about it.

His experience is named ‘hallucinations’ at this point. They had previously been ‘something interesting’ but during his appointment they became hallucinations, they were enacted into being hallucinations in the relationship between the doctor and Simon. The doctor sees the similarity between Simon’s story and other cases of hallucinations he has seen (Law, 2004). A diagnosis represents the universal rather than the particular.

Dave too describes

because I'm trying to think about first impressions of what are now called hallucination

Simon and Dave assert their own narratives of hallucinations but medical explanations impinge on their stories.

For nurses, the tensions between the textbook definitions of normal disease and individual patients in clinical practice was apparent

yeah there's lots of things that you could perceive as hallucinations and have been seen by GPs or other health professionals and have said they're hallucinating. But actually when you, if you get the chance and if you do work with them and build up a relationship, sometimes you're never entirely convinced that it is actually a true hallucination yourself

Although they were not always sure if what someone was experiencing was a ‘true hallucination’ they did feel secure in their own professional competence. They perceived hallucinations as an area of expertise for psychiatry.

Despite the explanatory hold that medical accounts have on understanding the origins of hallucinations, no-one thought that this was the only reality of hallucinations in

dementia. Everyone in the study considered living with illness as more important than suffering from disease.

8.4 Living with illness

Neither the participants who experienced hallucinations, nor their carers identified hallucinations in isolation, as a disruption to their lives. Bury's work on biographical disruption would suggest that dementia may have had a disruptive effect on the knowledge and structures of the everyday lives of my participants (Bury, 1982).

Two of my participants had experienced biographical disruption caused by differing illnesses for extended periods. Graeme had had a diagnosis of dementia for a number of years, and Dave had an earlier disruption with Parkinson's. In this extract we see how his taken for granted assumptions were dislodged and he and Joan had to re-examine their expectations for the future

it's obviously not what we, not part of the great master plan of life when we were 20 odd you know we thought what would happen when we were coming up for retirement, where we would be. Actually in one sense it hasn't made an awful lot of difference.

Dave has already reconstructed his life story to include Parkinson's, which is a longstanding diagnosis for him. Although he says that he thinks dementia may get worse, at the moment he will just wait and see, neither dementia nor hallucinations cause much more disruption at this stage. Williams (2000) revised the concept of biographical disruption by adding that timing and context can affect how people react to chronic illness. Illness can be normalised in certain circumstances: Dave is experiencing dementia and hallucinations within the context of long standing health problems. Graeme struggles with the battle between ill health and the expectations of a healthier old age

I cannae go and do what I used to be able to do and I know I know as we get older and things happen but I mean I'm no that old

For the people in my case studies, hallucinations did not threaten their self-esteem although for Graeme, dementia was beginning to threaten his sense of self. People balance both continuity and changes to their narrative identity.

8.4.1 Shrinking world

People with dementia may lose control of their space. Julia Lawton describes how a loss of mobility in people with a terminal illness leads to changing ability to negotiate space impacting on their selfhood (Lawton, 2000). Identity and place can be intertwined, not just home, but places that are part of our lives and through which we move (Teather, 1999).

There are a number of reasons related to accessibility that lead to people with dementia becoming isolated. These include mobility, way finding and perception problems. For all my participants there was a degree of altered mobility. Simon and Dave have both had to stop driving, which impacted on their identities

that's the worst thing is the loss of the car

Simon

The loss of the ability to continue to drive means a greater dependence on others that can result in friction. Simon and Jeanette discuss Simon's anxiety when she is driving on the motorway. She does not put this down to his mistrust of her ability but it has been difficult for them both. It can be a loss of autonomy that causes resentment for people with dementia

Joan: it's not going to change now

Dave: no but one day the medical profession might see sense

Different selves may be constructed in different places (Askham et al., 2007) but home is normally associated with security and identity. Graeme's house is his own space; he has religious icons and photographs of his children and grandchildren and also his own degree certificates on prominent display. He sits in a favourite chair surrounded by many of these photographs in easy view. Although he has security here even this is slipping at times, when things go missing

it's about a week ago since I've lost.. Where is this stick and every so often I go and have a search round. The only thing I can think of cos I wouldnae be able to go very far ... I would realise that I didnae have my stick with me, so the only thing I think I've done is I've put it in the bucket

Graeme's world is shrinking as he finds it difficult to negotiate crowded environments, he is unsure sometimes whether the people and animals he sees are real or not. Visuo-spatial difficulties can be associated with hallucinations in medical literature, where they are decontextualized, but Graeme describes their emotional impact. The hallucinations outside the house are distressing to him and he associated them with his perceptual difficulties. He blamed his perceptual problems on his dementia. His previous confidence has disappeared. One of the reasons he cites for not going out alone so often is that he does not want to 'make a fool of myself'. He restricts his movements to avoid potential loss of self-esteem. He ascribes this change, from a formerly outgoing person, to a less confident person, to his dementia. It could be argued that this is contributing to social exclusion but both Graeme and Lesley weigh up the disadvantages of this against the possibility of increasing his distress including disturbing hallucinations.

Frank (1997) reminds us that people who are stigmatized avoid social situations where they embarrass themselves and so upset others by losing control. All my participants experience some changes in their ability to communicate with other people or feeling safe going out alone. Dave has difficulties with his speech and his mobility associated with his Parkinson's and Simon also says he finds it more difficult to engage in conversation. Graeme and Simon restrict their own social activity but for Dave it is his physical disability that stops him from going out.

Dave is constrained by his mobility difficulties from going out alone but he sees his most vivid and entertaining hallucination from the safety of his home, looking out into public space. Although the things he sees outside are entertaining they can also point to the changes in the world outside. It has become less safe and predictable- there are people rushing around on motorbikes, and foreigners moving in. He becomes annoyed when the familiar becomes unfamiliar such as when he gets no response from the family members who he sees in his living room.

8.4.2 Lack of stimulation

The worlds of all my participants with dementia have been curtailed by mobility or communication difficulties. The nurses in my study identified people in care homes whose worlds have contracted. This can result in a lack of stimulation. Carers and nurses attribute some episodes of hallucinations to this sensory and social deprivation.

Previous research has found an association between hallucinations and sensory deficits especially visual impairment and visual hallucinations (Lawrence et al., 2009). Results from a recent study of hallucinations as reported by staff in a care home suggested that boredom could contribute to hallucinations (Cohen-Mansfield and Golander, 2012). Dave's wife Joan identified the losses he had experienced due to his Parkinson's. He is now unable to leave the house alone and has lost other abilities that were previously important to him. Joan wonders if the imaginative nature of his hallucinations could substitute for stimulation from previously used sources.

The professionals in my study also understood hallucinations as a source of entertainment for some people. People who are in care homes may have little else to occupy them. This could be a hint at a chaos narrative, an inability to move on to a future that would be worse than a present of imagination and entertainment and pleasant memories of the past.

Jeanette and Joan both considered hallucinations as a possible compensation for other losses. Joan says

maybe sometimes it's better to have hallucinations than think
about things that are actually happening

She is seeking to minimise the distress for Dave caused by his reduced ability to go out and engage the way he used to be able. This is not so much the concern described in much of the literature on loss for carers, but a concern by the carers for the impact of the losses on the person with dementia. It demonstrates an understanding for the needs for purpose and creativity, Joan's care is attentive to

Dave, and based on an intimate knowledge of him (Tronto, 1993). Her recognition of her own needs means that she continues to have a social life, sometimes without him which can contribute to his isolation. Good care can be complex in practice (Brannelly, 2011).

8.4.3 Distress

My criteria for inclusion meant that people who became disturbed talking about hallucinations were not included in the study, but nurses discussed people who became distressed. They described distress as a reason to intervene with possible medication, if no other intervention worked but it was very much a last resort

It's a quality of life issue then why would I want to treat with something or ask to have treated that could have all sorts of horrible side effects and you take away a source of pleasure or comfort for someone

Decisions about intervention are assessed as to whether or not hallucinations invoke anxiety or serve a purpose such as stimulation.

Threats to identity are often responses to difficulties in giving meaning to events. Graeme's hallucinations had been frightening for him when he was away from the security of his home. He had seen fierce dogs coming to attack him. He had less control in public space than in private spaces and felt safer at home. Graeme understood his hallucinations as part of his dementia and although he accepted some of them, there were certain hallucinations he found more difficult. If he found them disturbing he would spend time negotiating with his perceptions to try to understand them.

Lesley, Graeme's daughter found her dad's distress one of the most difficult things to deal with emotionally

I think the fear

I think that's a big thing

I think my dad being scared

I've never seen my dad scared

Dave does not tell Joan that he is hallucinating unless he wants clarification from her. Where there is no obvious evidence of Dave being upset, she does not inquire. It only becomes a focus of discussion when they perturb Dave, or if he thinks he has to collect his daughter, which might entail him forgetting he is no longer allowed to drive. In situations when he is distressed by the hallucinations Dave is able to ask Joan, who can reassure him, and he believes her. Joan's worry about him driving is about a situation that has never happened but can be a concern for Joan when she is out of the house. This creates a situation of uncertainty for Joan, it is a potential risk but

hopefully it'll not go down that route

She has not assessed it as something that needs to be acted on at the moment.

Rauol et al. (2007) in their edited work resulting from interdisciplinary inquiry found it impossible to differentiate between categories of illness, disease, disability and trauma but they described stories elicited as normative and disruptive. In this study participants distinguished between normative and disruptive stories. In normative narratives, hallucinations were accepted and woven into identity but disruptive narratives caused either a re-configuration of identity or it lead to chaos narratives. For the people with dementia and the carers this was a frightening experience and for the professionals a recognition of this fear was the signal for them to intervene.

8.4.4 Bodily control

Hallucinations are normally discussed as disembodied. For Graeme, they become embodied; they are part of his visuo-spatial difficulties. He has become uncertain of his body, and he finds himself dropping things more often. The body which is normally taken for granted, is making an appearance by becoming fragmented from his idea of his self. He describes cups of coffee jumping out of his hand and struggling to put on a jacket while holding a walking stick. His bodily sense of self is threatened by becoming a communicative body (Frank, 1997) that he does not recognise. His sense of self has previously included bodily control and this is disappearing.

Hallucinations become an outside force, although both he and his daughter recognise there is an incongruity in this

Graeme: and I think my brain cannae cope with things and it makes things up. It's no me that makes them up it's my brain (laughs)

Lesley: it's your brain aye (laughs) it's outside of you

Graeme's story of hallucinations is a self/other story in this extract. Analyses that place causes on the inside or outside of the self are inadequate and often involve more complex relationships. A cause may be placed outside the self but the illness affects many aspects of functioning.

Dave's relationship with his body and his hallucinations is different to Graeme's. His difficulty in controlling his body is very evident, looking at him. His Parkinson's has led to him finding it difficult to sit still but he does not tell a story of his body, his hallucinations are contained in his mind and this seems dissociated from his body. His body is, however, very much present to me in his narrative as I find myself uncomfortable with his apparent physical effort. Separating the narratives of hallucinations from those of dementia and other disruptive illnesses was not possible.

8.5 Hallucinations in relationships

All the people within each of my triadic case studies had a relationship with each other. Narratives take place within specific relationships (Somers, 1994, Carsten, 2007), they are not just co-authored with a researcher. Two of the carers within my study were co-resident spouses and the other was a daughter who did not live with her father but was an integral part of his life. Although Graeme lives alone he situates himself very much within a circle of relationships, especially with his family. His world has become circumscribed and his family are becoming more central to him now that his wider social circle is shrinking.

For caregivers hallucinations are located within interpersonal relationships. If identity is created in narratives then relationship identity can also be created within

narratives. The carers spoke about the impact of hallucinations within their daily lives and within a long term relationship. As Joan says

‘I mean they’re just part of our lives’

The hallucinations, which occur within the home are a part of Dave and Joan’s shared narrative; they are familiar members of their family but his hallucinations of the outside world are of unknown people. Even when his hallucinations may be dreams they are associated with memories from his past. This is part of his, and their shared narrative identity. Temporality changes in these instances. Chronologically the past becomes more vivid to him than the present.

Joan’s care decisions are made within their relationship that includes personal knowledge developed within a shared narrative identity. In an ethic of care framework this could be conceptualized as attentiveness (Tronto, 1993), Joan is attentive to Dave’s needs but does not disregard his reality either

Dave: Yes I think it's fair to say you've always been
supportive you know you've always seen my point of view ...
You may not agree with it, you may not see and you don't,
and think I shouldn't see whatever it is I see men on
horseback or boys playing in trees

Joan : well I don’t think any of us who don't have
hallucinations can understand what it is that you're seeing
you can tell us you can you can describe the picture

Dave is responsive to her. None of the carers disregarded the people with dementia. Dave and Graeme will ask their relatives if they are concerned about the reality of their hallucinations. Relatives reassure them when they become concerned about their visions.

All three people with dementia in my study were unsure of the linear temporality of some events and were corrected by carers, as in this exchange with Graeme and Lesley

Graeme because it’s one of the favourite things I tell people
about myself about my walking stick down my sleeve

Lesley see you get this all right where was this where did that happen

Graeme Dublin

Lesley it didnae happen in Dublin

Graeme was it no that's where I thought it happened

Lesley didnae happen cos ((husband)) wasnae with us it was Bruges

Graeme and Lesley both approach the situation with the humour established within an existing caring relationship. Sometimes the people with dementia asked for factual clarification from carers about the timing of events. During the time I spent with Graeme he would often refer to his daughter

Lesley will tell you about this

Sometimes he found his experiences so incomprehensible that he would suggest I seek corroboration from someone else to make them more credible.

Reminiscing is often inter-subjective, occurring within the context of relationships it can 'affirm a social relationship in its deep temporality' (Lambek, 2007: 220). Simon told me a story of an event that happened when he was small that Jeanette had obviously heard many times before. This story had obviously been told and retold and within this process had changed to become a joint narrative. Jeanette helped Simon to re-construct the story for me by joining in as a kind of Greek chorus

Simon: and er gave me whatever it was it cost a penny

Jeanette: it was your fare

Simon: that was my fare

Jeanette: aha it was a half fare

Simon: that's right and then the conductor

This enabled Simon to continue with the story. A number of times during my joint interviews, carers assisted the people with dementia to construct their narrative. Hydén (2013) described this as 'scaffolding' the storytelling when one of the

partners in the joint storytelling asks pertinent questions or offers possible explanations that allow the person with dementia to carry on as an active partner. Although the people in my study did not have the range of communication difficulties he described, this cooperative storytelling certainly happened with all my participants.

Lesley does not live with her dad and so has to work hard to understand the factual aspects of what has happened, and when. It is important for her to make sense of his narrative. This was easier for the co-resident wives in my study, although as I described earlier all of the carers provide factual details within shared narratives.

but it's taken me two days to make sense of something you
know and it is it's the second guessing and not being sure

Lesley

For carers it is often more than the need for day to day reminding that they see as a change within their relationships. Lesley describes the uncertainty of her relationships with her dad. Although he is not totally lost to her she is not sure about his status as a 'dad' any more. Her description of a dad as someone who is strong for his family starts to break down as she says 'a dad's never scared'. She balances the uncertainty of who her dad now is, with her commitment to their relationship. The name 'Dad' is used throughout the interview, in the Word cloud, it comes up as one of the three most common words she uses.

In many ways her dad is the same and very recognisable to her but in other ways their relationship has changed causing uncertainty. He was previously a strong person but has now begun to show fear at the hallucinations. He both is and is not a dad. Ambiguity defines their current relationship.

8.6 Multiplicity

The people with dementia and their families negotiate the medical classification of hallucinations within their everyday life. Nurses' understandings of hallucinations are not fixed but comprise a fluidity of different understandings. This was not simply a question of each nurse having a different understanding, but of them using

different understandings in different sites. This resonates with the work of Annemarie Mol in *The Body Multiple* (Mol, 2002).

Community mental health nurses enacted different versions of hallucinations in specific contexts. They were usually able to switch fluidly between versions without them becoming multiple but in a way that integrated them.

They told clinical stories to discuss hallucinations. Their stories showed how they situated hallucinations within specific situations and made clinical judgements based on a specific context. They use context specific knowledge

Context-dependent-knowledge and experience is at the heart
of expert activity

(Flyvbjerg, 2001 :p71)

‘Hallucinations’ was used as a term which acted as shorthand between professionals including myself, however it was not without its problems. A closer examination highlighted the multiplicity of its use; from the imposed order of DSM, to neurological changes within the brain, to the joint understanding developed between the nurse, person with dementia and carer.

8.7 Summary

To summarise: experienced community mental health professionals are skilled in negotiating the complexities and multiplicities of hallucinations through everyday clinical practice. They situate hallucinations within their professional knowledge that includes the disease model but they enact hallucinations and dementia within each clinical situation with the person with dementia and in the context of their relationships with significant others.

This study shows that by attending to the narratives of people with dementia who hallucinate we can gain an understanding of hallucinations as meaningful experiences for them. Previous studies of hallucinations and dementia have presented understandings based on de- contextualised knowledge of brain biology or epidemiology (Berrios, 1992, Leroi et al., 2003). The narrative of one of my

participants, Graeme, integrated hallucinations into a disruptive illness narrative of dementia. Simon and Dave integrated hallucinations into their biographical narrative identity, but not as part of an illness narrative. No-one used a single discourse to interpret their experiences they all used different discourses depending on the situation it described.

People with dementia integrate hallucinations into identity in a number of ways. They do this through inclusion in important aspects of their life such as skills or interests. Carers may assist in this. Shared narratives are collaborative constructions; they contribute towards the maintenance of relationships through facticity and structural assistance. Hallucinations cannot be seen in isolation from other aspects of illness and lives. Attributing hallucinations to identity is connected to the powerful modernist narrative of a continuing sense of self. As I described in Chapter 2, this is threatened by dementia in discourses attributing a loss of self to people with dementia. Hallucinations become a threat when they are anxiety provoking to the individual or to their relationships.

The ability of people with dementia and people with psychotic symptoms to tell the story of their illness has been questioned. Within dementia there may be an assumption that the ability to narrate is affected because of its association with memory, language loss and lack of awareness (Phinney, 2002). This can be compounded by associations of psychotic symptoms as synonymous with losing touch with reality (Lovell, 1997). This study has shown that it is possible to analyse the experience of hallucinations and dementia through narrative.

Exploring narrative understandings of hallucinations in dementia has developed understanding of how people with dementia manage hallucinations by integrating them within their lives. They adjusted by constructing meaning for them through their narrative identity. Hallucinations were assimilated into the self, which was refashioned to include both hallucinations and dementia. Previous literature has demonstrated how people narratively construct their lives incorporating dementia (Phinney, 1998, Phinney, 2002, Beard and Fox, 2008, Williams and Keady, 2006). Hallucinations have not previously been included in that framework of maintenance

of self. They are integrated into their narrative identity as both a continuation and as a change to their self-identity. They had understandings within a context of the practice of a specific situation.

Understanding narrative identity as being co-constructed, contributes to understanding hallucinations in dementia as an inter-subjective, not just an internal experience. There are often tensions between the different realities enacted and the narratives told. As in Mol's study this does not lead to disintegration but 'tensions are tamed' (Mol, 2002: 181). Realities in care practice are multiple and situated, care cuts across the tensions within knowledge leading to a fluid approach. The following chapter will locate the narratives of identity of people with dementia and hallucinations within a liminal space in which knowledge boundaries can be shifting and ephemeral.

9 Hallucinations in dementia as liminal

In the last chapter I examined how people with dementia, carers and nurses all used narratives to contextualise hallucinations. Ambiguity and uncertainty were characteristic of many of the stories of hallucinations in dementia in my study. In this chapter I develop a theoretical understanding of hallucinations in dementia by proposing liminality as a useful concept to describe and explore these experiences. Liminality challenges the fixed boundaries that can divide normal from abnormal and ‘in touch with reality’ with ‘out of touch with reality’. Liminality is a time of ambiguity and disorientation where normal boundaries are broken down (Turner, 1967, 1979).

In the brief introduction I revisit the theoretical understanding of liminality developed by Victor Turner and some of its applications in the field of health care. I apply a sociocultural understanding of liminality to dementia and carers, to explain why they may be marginalized. I then use an experiential understanding of liminality to understand the temporal and spatial disruptions that occur for people who hallucinate and have dementia. I also employ liminality to explore the emotional components, both distressing and more enjoyable of hallucinations. In the final sections, in keeping with an understanding of hallucinations in dementia as liminal space, I propose a role for professionals as master of ceremonies in caring for people, and within the ritual of diagnosis.

9.1 Introduction

The word liminal comes from the Latin *limen* meaning threshold. It was a term developed and used in anthropology to describe a stage during ceremonial rites of passage. Van Gennep (1960) described three stages when someone transforms from one status to another during rites of passage. The stages he conceptualised are a ‘preliminal’ or separation stage, a ‘transition’ and a return to a new status (Turner, 1967, Felde, 2011). Turner further conceptualised the transition or liminal period, which he described as a time of ‘betwixt and between’ (Turner, 1967:93-111). He applied the understanding to both small scale and larger societies. The transition that occurred, according to Turner was a process or a transformation. The person in the

liminal space is neither one thing nor the other; they have left behind one status and have not yet moved on to the next, although they may exhibit aspects of both. Liminality is not a static state but a confusion of usual categories, ambiguity and disorder. It can be either positive or negative as society bestows on the person a specialised status, it does not necessarily isolate people, they may also experience camaraderie in their seclusion which allows them to be themselves without having to conform to institutional roles (Turner, 1967, Jackson, 2005).

Against this background the theory of liminality has been used in the field of health in recent years to analyse conditions where the person feels healthy but has clinical signs of abnormality. Examples of this are in the management of raised cholesterol (Felde, 2011) and having an abnormal cervical smear result (Forss et al., 2004). Liminality has also been used in approaches to chronic health problems for example chronic pain (Jackson, 2005), cancer (Little et al., 1998) and mental health issues (Warner and Gabe, 2004, Barratt, 1998). There may not be a resolution to another stage, instead people might continually live in a liminal state. Liminality within health studies has predominantly addressed the structural impact of being assigned a social category that impacts on the way they are viewed by society. I would argue that alongside this social account, liminality can also contribute to understanding the psychological and emotional experiences of hallucinations in dementia.

9.2 Dementia and hallucinations: liminal persona

I discussed in Chapter 2 the ways in which someone with dementia can challenge the modernist idea of what it is to be a person. The modern person is a rational and independent individual. A person, who does not fit these criteria, because they may see things that others do not, and may require care, does not belong in this social category.

It can be argued that people with dementia are in a liminal space due to their ambiguous status, transgressing the dualistic boundaries of both health and illness, and life and death. They do not fit easily into social categories. Turner describes the symbolism ascribed to the liminal identity as ‘structural “invisibility”’ (Turner, 1967: 96), which may even encompass symbols of death. Some popular images have

assigned descriptions such as the 'living dead', to people with dementia (Aquilina and Hughes, 2006).

Barratt (1998) argues that the 'schizophrenic' straddles the boundary between a person and a non-person, and this perception could equally apply to a person with dementia, especially if they experience hallucinations. In terms of some of the views of a self discussed in Chapter 2, they may be neither a person nor a nonperson. The consequences of this position are that people are avoided because they are viewed as bizarre and dangerous.

The work of Mary Douglas (1966), alongside that of Turner, has provided an explanatory frame for Barrett's understanding of the position of people with schizophrenia, and Lawton's (2000) understanding of the fear and anxiety aroused towards the dying. Douglas (1966) explains the crossing of classificatory boundaries as a transgression, resulting in 'pollution'. She concludes that ambiguities are regarded as ritually unclean and are therefore a source of potential danger.

The work of Kitwood (1997), and many others since, has identified the difficulties experienced by people with dementia when they are denied personhood. The professionals in this study indicated that people with dementia living in care homes were often misunderstood by staff working there. Sometimes they did not recognise that people were distressed, when the mental health nurses thought they clearly were, or care home staff either did not make the effort, or were unable to establish a relationship with the person with dementia. Establishing relationships is central to the ethic of care literature (Tronto, 1993, Barnes, 2012). Understanding of the liminal persona of dementia can help to explain the difficulty experienced by residents in care homes. According to Turner 'neophytes' as he describes those who have been separated from one status but are not yet integrated into another 'have a physical but not a "social" reality' (Turner, 1967: 98).

Barrett, in his case for the 'schizophrenic' as 'liminal persona', ascribes the diagnostic inability to understand schizophrenia as further evidence of its ambiguous status. He compares it with dementia, which he describes as 'neuropathologically

explicable' (Barratt, 1998: 476). As we have seen in the review of the literature, a diagnosis of dementia is only probable, 'there is no hard scientific boundary between disease and normality' (Hughes et al., 2006:2). People with dementia may feel healthy and live their lives as though they do not have a disease. The nuns in the Nun Study (Snowdon, 2001) sometimes lived without symptoms of dementia, when on post-mortem they were shown to have pathological damage associated with Alzheimer's Disease.

Hallucinations in dementia are also contested, as evidenced by the variance in prevalence rates (Bassiony and Lyketsos, 2003). They present a challenge to medicine in that there is a diversity of suggested treatment options. Unlike hallucinations in schizophrenia, treatment with anti-psychotic medication is not the usual treatment of choice due to mixed reports of efficacy (Bassiony and Lyketsos, 2003) and the risk of side effects (Banerjee, 2009). Jackson (2005) argues that people who have chronic pain have an ambiguous status as they transgress dualistic boundaries in similar ways to liminal states. It can be argued that people with dementia and hallucinations are in a similar situation.

When people enter a liminal state they

May be said to be in a process of being ground down into a sort of homogenous social matter in which possibilities of differentiation may still be glimpsed

(Turner, 1977: 37)

People with dementia have had to fight and continue to do so to be seen as **people** living with dementia rather than as a homogenous group called 'dementia sufferers'. In this study the way in which the people with dementia and their carers made sense of hallucinations and dementia within the context of narrative identities, demonstrates their refusal to accept this position as liminal personae. However, their selectivity about who they told their diagnosis to showed they were aware of the social impact that the diagnosis of dementia retains.

Arguing that people with dementia and hallucinations can be described as ambiguous runs the risk of appearing to endorse the idea that they are non-persons. I wish to use

liminality instead to argue that ambiguous categories can be used to socially exclude people who do not fit. The way that dementia and hallucinations are constructed as categories has social implications for people, it positions them within society. Carers too have been positioned as living in ambiguity, and in the following section I discuss how this was understood by the carers in my study.

9.3 Carers and liminality

Much has been written about carers of people with dementia experiencing a living bereavement due to the changes in the identity of the person with dementia. This has been the traditional model of research into carer experience, focusing attention onto the deviation of people with dementia from the norm. It can also create a boundary between the experience of the person with dementia and the carer, rather than examining the impact of dementia on a relationship

All the carers I interviewed describe some changes in their relationships. They experienced some ambiguity as they transgressed the previous roles on which their relationship had been built. In his conceptualisation of Self 3, Sabat (2001) describes the recognition from others as essential if a role is to be maintained. When carers experience ambiguity, this can make the Self 3 of the person with dementia vulnerable as they may not affirm their roles.

All the carers supplemented the memory of the people with dementia to some extent. Examples were providing the day to day remembering of appointments or assisting with temporal sequencing of events. Carers often had to negotiate with statutory services, advocating for services for the person they care for. This failed at times as it did for Lesley who describes her anger at the withdrawal of a specialist home care service her dad used to receive. She now feels unsupported, as the available services are inappropriate. For Ryan and Runswick-Cole (2008) the lack of recognition of the expertise of carers can contribute to their liminal position. This resonates with the findings of Galvin et al (2005) of the carer as a liminal figure who builds bridges between the private world of a person with dementia and the public world of health and social care. Galvin et al (2005) describe the carer as an 'intimate mediator' who

has the knowledge and passion for the person with dementia and acts as translator for the outside world and also for the person with dementia regarding the outside world.

The people with dementia and their families who participated in this study negotiated the medical classification of hallucinations within their everyday life. As Joan said of Dave's hallucinations 'they are part of our lives'. Although the two wives integrated some medical explanations of hallucinations into their understandings, they both negotiated them within their life world. None of the carers placed themselves within the discourse of living bereavement but as continuing to live within a relationship.

Although my participants with dementia and carers challenged being positioned as socially excluded as individuals, they were aware of the stigma that could be attached to dementia. Liminality provides a useful framework with which to understand the structural positioning of dementia and hallucinations. In the following sections I use liminality to understand the psychological and emotional impact of dementia and hallucinations. Liminality has temporal and spatial aspects, and I will use these in the following sections to explore the temporal and spatial disruptions that can result from dementia and hallucinations.

9.4 Disrupted temporalities

9.4.1 Temporal structures

Time is a fact of social life but it can be understood in a multiplicity of ways as Barbara Adam (2004) explores in her comprehensive study. Lived time is mostly understood as linear; this is a way in which humans have attempted to control time and the rhythms of the natural environment (Adam, 2004, Adam, 2006). Time is normally structured and ordered by clocks, calendars and sequences of events (Shomaker, 1989). We also live time through repetitions of seasonal and cyclical changes, bodily biorhythms and habits and routines (Adam, 2010). People experience time as an extended awareness of the past and future in the present. Perceptions of subjective time may change in chronic illness (Little et al., 1998). Liminality is a time of ambiguity and the subjective experience of time may be disrupted.

9.4.2 Chronic liminality

Recent literature on chronic illness and liminality has begun to explore liminality as a way of life rather than a transition (Kelly, 2008, Jackson, 2005, Murphy et al., 1988). Kelly (2008), in her study of the impact of AIDS related dementia explored the impact of living with loss and dying as occurring within liminal space. This addressed not just the socio-cultural, but also the psychological attributes of liminality. To understand hallucinations as liminal situates them both within the sociocultural context, and within the inner, private context of the individual..

In this study hallucinations occur within the context of dementia and they need to be considered together as they were presented in the narratives of my participants. Dementia is a chronic illness, but hallucinations may change and disappear. They may become more or less frequent, threatening or benign. Chronic illness causes temporal disruption, it disturbs the normal patterns of everyday life (Bury, 1982, Williams, 2000). Illness can threaten previous expectations for the future, causing temporal interruptions (Frank, 1997). When Graeme wishes for a future in which he is unable to remember, he is challenging the expected narrative ordering in which an imagined future is part of a temporal sequence. This future he expresses a desire for is paradoxical, he is telling a story of self in which his self disappears. It is the unmaking of a narrative temporality. This presents a challenge to illness narratives like the restitution narrative where there is an expectation of a return to health, but neither is Graeme's story a chaos story. A chaos narrative involves life never getting any better, in this story life does get better but by getting worse.

The routines of people with dementia are often dis-ordered; it may take them longer to carry out routine tasks that can be more tiring. Periods of fatigue in illness can dislocate previous temporal habits of being (Irving, 2005). In my study, both carers and people with dementia described tiredness and sleeping longer as factors in their hallucinations. One of my participants described the time and energy he had to expend on working out whether something was a hallucination or not. His life was constantly interrupted by difficulties, whether losing things, working out his perceptions or normal daily activities. People who hallucinate may spend time trying

to distinguish reality in their perceptions. People with dementia often become isolated within their house leading to changes in their perception of time passing.

9.4.3 Time and memory

Memory is normally a process rather than a discrete object (Ferryhough, 2012). It is only when there is some identified difficulty with it that it becomes objectified (Lambek, 2007). Reminiscence is normally an active process, but for people with dementia it becomes a discrete problematic entity, symptomatic of disease that needs to be regularly measured and indicative of cognitive state. Time and memory are not linear, but the coherence and authenticity of stories of people with dementia are often viewed as suspect. In the previous chapter, I described how people with dementia and carers often co-constructed narratives, and when there was a difficulty with linear temporality, this was especially evident. Although memory is notoriously unreliable for everyone, people with dementia have more difficulties in configuring clock and calendar time, there are more likely to be slippages.

Shomaker (1989) found liminal time a useful paradigm for the temporal disorientation in Alzheimer's disease and I would argue that it is especially useful to understand the realities of people who are hallucinating. Merleau-Ponty (1962) says that memories are not associations but re-open time lost and allow us to re-evoke it (cited in Thomas et al., 2004). The past memories of my participants, and the people with dementia that were discussed by the nurses in my study, sometimes became more real than events that were happening in chronological time. What may seem to be chaotic perceptions may often have an unseen logic. In their desire for narrative coherence, nurses looked for reasons for particular hallucinations such as memories of past events. These may be traumatic as in the case of the man who had been a Japanese prisoner of war and thought he was imprisoned when in a hospital ward, or of previous occupations as when someone was reeling in a fishing line.

According to Ricoeur (1984), time becomes meaningful through narrative. It is through the structure of narrative that human experience of time can be made sense of and communicated. People live and interpret their lives in relationship to time; temporality becomes interpretable in human terms through narrative. Carsten (2007)

argued that narrative is consciously used to make continuities, and shared narrative memory stabilizes a sense of self within kinship in the West. If this sense of continuity is dislocated because of memory difficulties it can result in discontinuities with the shared narratives of others and the possibility of a shattered self. These may be the situations when carers express ambiguity about the person being a different person. In my study, people with dementia were able to locate themselves in the present, but sometimes they had vivid memories of the past that risked becoming more present than the chronological present. Disruptions to continuities in differing communities and situations led to establishing continuities in other ways within an edited collection of anthropological studies (Carsten, 2007). Loss of memory for current connections can lead to a search for connections in time further back, as in situations where people with dementia search for their parents. Although none of my participants had lost connections in this way, Dave told of a vivid dream in which his mother appeared to reassure him that things would work out. The nurses also told of people they had known who were feeding photographs of children or grandchildren at a younger age, perhaps searching for connections with a life where meaning involved providing for a family.

Frank (1997) describes illness as disrupting the narrative coherence of life as a sequence, because illness experiences become too vivid to consign to the past. In dementia there can be a disruption of narrative sequencing, resulting in difficulty in distinguishing between past, present and future. Boundaries become leaky and this may contribute to hallucinations. My study adds to Shomaker's (1989) theorizing of temporal disruption as liminal in dementia by adding hallucinations and chronic illness to the discussion. Liminality and biographical disruption enhance understanding of the temporal disruptions of dementia and hallucinations, contextualizing them, rather than attributing them solely to a biochemical deficit without meaning.

9.5 Spatial liminality

Liminality can disrupt spatial certainties. One of my participants described an experience that could be described as an alternative spatiality. He had the feeling

that the house in which he was living was somehow alien, although it appeared like his house, it was different. His description of this was fragmentary. For another participant it was their experience of the outside world that was spatially disrupted leading to a self-imposed social isolation within the safety of his home. Discussing collective rites, such as those occurring at certain important changing points of the year, Turner (1979) distinguishes between everyday public space and space that has been partitioned off as liminal space. In hallucinations and dementia these may be the physical spaces of care homes that are set aside for people who are older and have some health problems.

The boundaries for the person with hallucinations between public consensus reality, and internal imagination, may also leak. Internal imaginings and dreams may seem to be as real as consensus reality and common sense logic can be applied to explain it. Dave responds to my question about seeing anyone in the trees on a windy day as they would be very foolish to be there in that type of weather. Common sense logic is employed in a situation where it does not appear to other people that it should fit. His knowledges seem out of synch.

9.5.1 Isolation

Turner describes societies in which people in a liminal state are secluded. They are either removed to a physical place of seclusion, or they may be hidden from view behind masks. In the past people with dementia have been removed to either hospitals or care homes, rather than integrated into dementia friendly communities. Murphy et al (1988) describe the seclusion of people with physical disabilities due to mobility difficulties as similar to a liminal state, and I would argue that this applies equally to people with dementia, who may be isolated because physical and communicative difficulties make it difficult for them to engage with the community.

All three of my participants with dementia had limited access to the public spaces in which they had previously moved with ease. The reasons for this and the degree of this varied but they found more barriers than before they had dementia. Contraction of time and space results in a greater likelihood of isolation that may lead people to seek other sources of stimulation.

All the nurses in the study discussed care homes in relation to hallucinations. They supported an understanding of isolation as a contributing factor in hallucinations. Their framing of hallucinations as a response to isolation is echoed by the two wives in this study.

Joan wonders if the hallucinations are preferable for Dave than facing the reality of being isolated within the house as he has become less able to get out. Jeanette too sees the hallucinations as compensation for the other losses associated with dementia. Understanding spatial isolation as liminal allows us to explore the other aspects of liminality described by Turner (1977), which includes the suspension of normal structures, allowing reversals to occur.

9.5.2 Perceptual liminality

The relationship between social reality and their own private reality changes for the person with dementia who has hallucinations; they straddle the boundary between real and imaginary. Experiences which people within Western society would ascribe to a private reality, such as dreaming, begin to slip into the social realm where one would anticipate consensual reality. The three people in my study were mostly able to distinguish between what would be viewed by others as an external reality, and dreaming or imagination, but the latter assumed a greater importance than previously in their lives. There was often ambiguity in reality and the professionals gave more examples of this happening. These included people acting on the other reality, feeding photographs or leaving their house in the middle of the night to escape music.

9.5.2.1 Dreams

In my study it was Dave who spent much of our interviews discussing dreams although the other two also described them to a lesser extent. Dreams can become a metaphor for hallucinating. Hallucinations are described in terms of another concept, dreaming. Hallucinations are not something that can be easily described even by the people who experienced them, and one way of discussing a difficult concept is through metaphor. Both hallucinations and dreams are difficult to describe but are connected by the associated change in consciousness. They are also personal

experiences. We can listen to the dream of another but we cannot enter into their dream and experience it.

When we use metaphors to describe an abstract concept, we often compare it to something which is concrete, although a single concrete comparison is never quite right (Lakoff and Johnson, 1980). Metaphor can be a useful way to explain something that is difficult to describe but in this case it is compared to dreaming. One elusive term is explained by another, the contents of individual dreams may be difficult to convey but most people have experienced dreams. Metaphor provides us with a shared understanding.

Both dreaming and hallucinating are intangible, and another way of understanding them would be to view them as liminal. The way Dave and Simon thought of dreams and reality was uncertain and mysterious. The discrimination between social reality and imagination becomes less important in hallucinations and dementia. Perhaps this is why it appears that boundaries slip for the listener and the speaker when talking to people with dementia and hallucinations. Liminality is a time and place of ambiguity; the perceptions of reality of people who hallucinate can be ambiguous.

The linkages between hallucinations and dreaming, or between private reality and consensus reality, are unclear. Dave moves between dreams and hallucinations without always knowing the difference. The supposition that his reality and mine differ assumes a boundary between them, but sometimes our realities coincide. The boundaries slip and become permeable, and so his reality, of the wind being unsuitable weather for boys to climb trees, was the same as mine, as was the reality of whether the cricket season was over. These sorts of slippage happened frequently in my study.

The problem with boundaries is that they can become stable and set up oppositions which may not exist (Mol, 2002). Boundaries are flexible and permeable within the liminal space. An understanding of liminality allows a space that is unstructured and in which it is possible to step outside the mundane. My participants sometimes explained this as imagination.

9.6 Hallucinations as imagination

Turner describes liminal time as ‘a time of enchantment when anything *‘might’* and even should, happen’ (Turner, 1979:465). It is not necessarily a negative experience, but can be a time when people can enjoy themselves without having to conform to institutional roles. It is similar to carnival, where the normal order is disrupted (Turner, 1979). Liminality allows new options for creativity as people are not constrained by the established order.

Descriptions of hallucinations usually emphasise the serious, and the ludic, inventive aspect is ignored. Hallucinations can be creative and a source of imagination, they can entrance. Roles have responsibilities and ‘neophytes’ who are in a liminal space can

“be themselves”.when they are not acting institutionalized roles

(Turner, 1967:101).

As one of my participants argued ‘but you can see things in almost everything you look at’, he and his wife both viewed his experiences as aspects of his artistic imagination which was somehow more authentic than mundane everyday reality.

Most of the participants in my study understood some experiences of hallucinations as entertainment. In situations where there is a lack of other stimulation it was felt to be comprehensible and harmless. Liminality can explain the playfulness of some aspects of hallucinations within dementia.

Imagination, humour and ephemerality are considered inconsequential; they do not constitute the serious knowledge of objective truth. Liminality troubles this understanding of knowledge

Reality isn’t large enough to hold us

(Neilsen, 2002: 211)

Knowledge too is shape-shifting like hallucinations, it is contextualized and impermanent.

9.7 Chaos

As in carnival, a disruption of the usual order can cause playfulness, but this is never far from anxiety. The flip side of hallucinations as entertainment is that they may become nightmarish. People may be unable to escape from scenes of their past. The mental health staff were also able to recall episodes of fear in people they had known. This turmoil is described by Frank (1997) as a chaos narrative. Chaos stories lack narrative order and are difficult to listen to. Some stories of hallucinations are like this: when told, they induce anxiety. They are anti-narratives where time does not have sequence and there is no control (Frank, 1997: p98). Narrators may be stuck in the experiences of the past and are unable to provide a coherent narrative with movement through time. There is no sense of future or of agency in these chaos narratives. The narrator is not an active narrator, but a passive victim of the past, which has become a recurring nightmarish present.

Chaos narratives may not be told unless one is at a distance and so can reflect. If there is the temporal disruption described earlier, and someone is unable to escape a frightening present, whether that is a memory of the past that has slipped forward into the present, or a dream or imagining that has slipped through to reality then it can become a chaotic story.

The chaos that may ensue in these narratives is difficult to listen to, and causes fear in the listener. This is akin to the fear described in the earlier section about dementia and schizophrenia. Frank (1997) argues that there is a moral duty to listen to a chaos story despite the discomfort that this can cause. This has implications for nurses whose role as master of ceremonies is discussed in the next section.

9.8 Master of ceremonies

Liminality breaks down established boundaries and may cause chaos for the person who is in the liminal space. It might become difficult to know how to act in this situation, as previous certainties no longer apply. The person may look for figures that can steer them through this time. In the rituals studied by Turner (1967) and van Gennep (1960) there is a Master of Ceremonies who leads the neophytes through the liminal space from one status to the next. For the purpose of this discussion I

would suggest that this is likely to be a member of the Community Mental Health Team. Doctors and nurses have different roles in the rites of passage for people who hallucinate. Doctors may perform the ritual of diagnosis, but nurses have a role in helping people to adjust to a diagnosis.

9.8.1 Nurses

Nurses assist people with dementia to live with their symptoms, they help the person with dementia, and their family to negotiate the medical world and their everyday life. The nurses in my study positioned themselves as experts in professional knowledge of dementia and mental health problems and were therefore eminently suitable masters of ceremonies. The day-to-day work of these nurses does not involve generalities, but working with specific people. This is how they approach people with dementia and hallucinations: getting to know them as an individual and deciding what is good for this particular person. They use what Mol (2002) calls indication criteria to decide how to treat their patients. The nurses in this study concluded that the main indication criteria for intervening in hallucinations should be distress. They obscure the implicit boundary between real and not real in favour of the boundary between distressed and not distressed. They try to achieve order in the chaotic world of hallucinations.

Using an understanding of liminality, the novice receives instruction in skills needed to live in their new status. As described above, the chaos that may ensue from the hallucinations and dementia, can affect knowledge of everyday life. The findings from this study suggest that nurses act as facilitators for people with dementia and their families, helping them to develop ways of managing their hallucinations and dementia. They use their expertise within the context of a therapeutic relationship.

Stories have to *repair* the damage that illness has done to the ill person's sense of where she (sic) is in life and where she (sic) may be going.

(Frank, 1997: 53 italics in original)

Nurses make successful masters of ceremonies when they are able to assist someone to move along from a permanent repetitive present, which is causing distress, to

being able to imagine a future without anxiety. This means that they have to listen to the story within an empathic relationship.

9.8.2 Professionals as betwixt and between

Nurses too are betwixt and between. They can be between people with dementia and other professionals as in the narratives of negotiating with staff in care homes and sometimes in negotiations with other professionals. They also described the dualism between person-centred care and the organisational demands that they face. As Lapum et al. (2012) argue, nurses adopt a 'cyborg ontology' (p276) in their negotiations of the boundaries that are inherent in their day to day work.

These boundaries can be between knowledge practices, that of biomedicine and the knowledge of the person who hallucinates; they have to make a singularity out of the particular situation of practice in a specific relationship. This may require that they keep different realities separate or they distribute them across time or space (Mol, 2002).

9.9 Rituals

Turner (1977) described how people who entered a liminal phase were ground down and made to look stupid in the liminal phase of a rite of passage. Cognitive tests such as the Mini Mental State Examination (MMSE) (Folstein et al., 1975) can demoralise people with dementia (Sabat and Harré, 1994) and if it is used without context can lead to testers making assumptions that adversely affect treatment. For one of my participants it was the opposite effect that concerned him. He had a passionate interest in politics throughout his life and had studied the history of British constitutional politics. He argued that asking him who the Prime Minister was would give people a totally false idea of his functioning in other areas as he could remember every Prime Minister of the twentieth century.

Diagnosis has its own norms and rules and has been described as a ritual (Sadler, 2004). In my study the participants referred to the change from their private experience to being given a diagnosis of hallucinations. Their doctors, usually psychiatrists had the role of leading them to a diagnosis. Doctors are the experts who

are trusted and initiate people into a diagnosis of hallucinations. Initiatory rituals have the specific process, of moving people from one status to another. The doctor can take someone to a position of ‘person with a diagnosis of dementia’, and to a position of ‘person with hallucinations’. It is a rite of separation in that the person becomes separated from the world of consensual reality and enters a liminal state. In psychiatry the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 2013) acts as the book of spells. As described in the literature review this is not without its problems.

Diagnosis simplifies disease and symptoms into a classificatory system, and in turn ignores what does not fit; it creates order. It is a fundamental aspect of medicine, it names and gives an explanatory structure (Bracken and Thomas, 2005). In the context of biographical disruption, diagnoses can be understood as important for people for whom the disorder caused by chronic illness is so disruptive that it profoundly challenges their previous knowledge of everyday life (Bury, 1982). Diagnosis provides structure within a reality of illness. A ritual can be an active process that makes a change in a situation (Moore and Myerhoff, 1977) and this insight assists in understanding why people with dementia and their carers might look for a diagnosis. Seeking a diagnosis can be seen as an attempt to create order out of the chaos that exists in the liminal space described above. Graeme found it difficult to lose his diagnosis of dementia with Lewy bodies. It put him back into a position of uncertainty.

The DSM creates new ways for people to understand themselves (Pickersgill, 2011). It can separate the disease from the self, although this can be a difficult balance to maintain when chronic illness can affect all aspects of life (Bury, 1982). This ambiguity was recognised within the narratives of my participants.

Turner (1977) argues that a ritual is not necessarily a static occasion but can potentially be flexible and interactive. Mol (2008) makes the distinction between diagnosis and treatment and the knowledge needed for them. They are distributed as different moments over the person’s itinerary. Diagnosis should take into account the personal narrative and understanding of the person with the illness (Bracken and

Thomas, 2005, Hughes, 2011), it should be a 'situationally specific' (Moore and Myerhoff, 1977: 12) , ritual not merely symbolic.

As we have seen, a diagnosis within psychiatry is value laden, and dementia as a diagnosis is not clear cut (Hughes, 2011). I would concur with Hughes that diagnosis still has a place for people with dementia as long as it is embedded within an individual human perspective. I find the term 'hallucinations' within the context of dementia is more problematic. The nurses in my study all understood the stipulation of hallucinations in my inclusion criteria, but in their narratives they all began to question whether people had what one of them called 'true hallucinations'. Slippages between hallucinations, misperceptions, and memories becoming more prominent, were common in the findings presented here. Perhaps the use of the term should be re-thought and there should be more emphasis on the actual experience of the person with dementia. The 'Hearing Voices movement (Hearing Voices Network, 2013) has had some success in challenging the terminology of hallucinations in people who hear voices. The people in my study all had visual experiences, but slippages described by the nurses are common and have been identified in previous literature (Ffytche, 2004, Lawrence et al., 2009). 'Hearing voices' describes an experience, which is situated within a personal and cultural history (Thomas et al., 2004). A more situated description of the experiences of people with dementia would provide a more useful person-centred understanding.

9.10 Summary

Living with hallucinations as a person with dementia, or as a carer can involve transitions. Understanding this transition using the concepts of separation, liminality, and rebirth into a new social category, allows us to examine the ambiguous sociocultural invisibility of people with dementia and people who experience hallucinations, increasing our understanding of their marginalisation. Using a framework of living in a liminal space can lead to an understanding of the experience of hallucinations in dementia as an ambiguous and paradoxical experience. As Edith Turner wrote

I couldn't find it in me to go out of my way to invent complicated explanations involving the social construction of reality and hallucinations, just in order to avoid what was in plain sight: the nonlogical

(Turner, 2005: 258)

Liminality is not a purely negative experience. It can free people from constraints and allow a time of playfulness and possibility. Hallucinations and dementia are often assumed to be unpleasant, but liminality provides space to disrupt and challenge previous boundaries. Finally an understanding of the role of nurses as master of ceremonies, enhances appreciation of their skills in negotiating the multiple realities of hallucinations of dementia within an ethic of care.

10 An ending

The findings from this thesis provide a contribution to our knowledge of hallucinations in dementia as understood by people with dementia, carers and community mental health nurses. This contribution challenges the dominant understanding of hallucinations in dementia, which actively excludes other perspectives, resulting in the invisibility of the contextual surround. This has negative implications for the social experiences of the person with dementia and is inadequate to understand the experiences of people with dementia, carers and nurses. It fails to allow a space to discuss the co-construction of hallucinations as they are lived within relationships and in interactions with mental health professionals.

My work makes a methodological contribution to the examination of hallucinations in dementia from the perspective of people with dementia, their carers and mental health nurses. It contributes to the debates of how the self is preserved in dementia especially when hallucinations are present, and points to liminality as a useful concept for understanding hallucinations within dementia. In addition, it contributes to an understanding of how community mental health nurses work with multiplicity, and how hallucinations are understood within relationships, both by people with dementia and their carers. This chapter will explore these contributions to knowledge.

10.1 Methodological contributions

Previous studies of hallucinations in dementia have not addressed the contextualized understandings of hallucinations in dementia, but have understood them as decontextualized pathological experiences. This study has challenged this and contributed to the literatures that examine the perspective of the person with dementia and their shared narratives by adding an understanding of the narratives of hallucinations.

10.1.1 A lived experience: narrative approach

Where the dominant discourse of hallucinations is that they are a biochemical deficiency, the person with dementia remains a passive victim of these changes, and

their experience is silenced. There is no room for the understanding of hallucinations as meaningful experiences that happen within biographical and sociocultural contexts. My methodology provided a space to go beyond the medical understanding.

A narrative case study approach using unstructured interviews enabled me to gather rich data from all participants. Understanding interviews as narratives, in which narrative identities were constructed, allowed me to attend to the narrative resources that people with dementia and their carers used to understand hallucinations within the context of their biographical lives. As discussed in Chapter 2 there has been a growing body of research that has addressed the experience of the person with dementia, but the experience of hallucinations has been absent from this literature. This study shows a methodological approach that has begun to address that gap. Narratives of people with dementia who hallucinate have previously been unheard by researchers; this study demonstrates a way of attending to their narratives, rather than privileging those of other people. It supports the findings of other studies that have shown the importance of narratives for making sense of experiences of dementia (Robertson, 2013, Beard and Fox, 2008, Cayton, 2004), and hallucinations (Woods, 2013).

The expansion of narrative inquiry has resulted in a focus of interest on the experience of illness and also that of the narratives practised within medicine (Hydén and Brockmeier, 2008). A triadic case study approach has allowed me to listen to the different and joint narratives of people with dementia, carers and nurses. This has produced a rich description of the multiplicity and complexities of hallucinations and their co-constructions.

The understandings of people living with dementia, including carers were partially congruent, but carers were more likely to add additional narratives of biographical disruption. They understood the content of hallucinations predominantly as biographically explicable, and their cause as compensation for losses that come from chronic illness. The addition by Williams (2000) of diversity of age, previous health and life experience, to chronic illness as biographical disruption (Bury, 1982) is

supported by the data in this study. Hallucinations are understood within the context of narrative identity and biography.

The authenticity of narratives of people with dementia and people with psychotic symptoms has been questioned (McLean, 2006, Lovell, 1997). Within dementia it is often assumed that the ability to narrate is affected because of its association with memory, language loss and lack of awareness (Phinney, 2002). This can be compounded by psychotic symptoms, which are synonymous with losing touch with reality (Lovell, 1997). My methodology demonstrated that the participants with dementia in this study were able to construct coherent narratives of their hallucinations and as such challenged methodological assumptions regarding people with dementia.

10.1.2 **Sense of self and 1-poems**

Doucet and Mauthner (2008) highlight the ‘multi-layered interpretative approach’ of the listening guide. It allows an in-depth exploration of the ways that people talk about themselves. The creation of I-poems allows the listener to follow how the speaker represents themselves by attending to their first person statements (Edwards and Weller, 2012).

In Chapter 2 I outlined some of the on-going debates about whether the self remains in dementia. The understanding of selfhood proposed by Sabat and Harré (1994) and further developed by Sabat (2001) is that it can be understood within a framework comprising three aspects.

- Self 1- is the sense of identity that is experienced as continuity in the world
- Self 2- is the physical and mental attributes we have, and our attitudes towards them
- Self 3- is the way people present themselves. This is the self that is most vulnerable as it requires acceptance from an other

(Sabat, 2001:17-18)

These understandings are similar to the explanation by Somers (1994) of the 'ontological narratives' that we use to define who we are and what we do. Sabat (2001) argues that the use of first person pronouns is indicative that a sense of self is maintained in dementia (Self 1). Using first person pronouns is assumed to be a public expression of an inner process of self-awareness (Aquilina and Hughes, 2006). Attending to these indices through the second reading of my analysis allowed me to trace the way that the participants represented themselves. I do not believe that this results in knowledge of a 'real self' of the research participant, but it does illustrate that everyone, especially the people with dementia, in my study expressed a sense of self.

Distilling the interviews down to I statements and I-poems in particular in my study cut out the extraneous speech that might be seen as confused. Shakespeare (1998) explores how despite confused speech being an accepted part of normal conversation, when it is identified in a group deemed to have less competence than others, like people with dementia, it begins to be seen as problematic.

Presenting the data as poetry offers a way that a different voice can be heard. The use of poems slows down the words, giving the listener an opportunity to take more time in hearing the voice presented. These are not formalised poems written by a skilled wordsmith but I would argue they retain some elements of what makes poetry speak. The poems speak to me of emotional knowledge, but I bring to my interpretation a belief in the value of emotional relationality.

Knowledge from stories is more likely to generate emotional reactions (Polkinghorne, 1995) and I found the I-poems particularly powerful in this regard. Attending to the emotional responses of people with dementia can contribute towards supporting well-being. Aesthetic ways of knowing that are acquired through emotional engagement are integral to providing good care (Stenhouse et al., 2013).

The analysis presented here demonstrates that hallucinations in dementia do not result in a change in Self 1 in people with dementia; hallucinations did not present a threat to their sense of self. This is in contrast to an understanding that a person with

dementia and a person who experiences hallucinations are a different person because they lose contact with reality.

10.1.3 Answering the research questions

The research aim was to explore different realities of hallucinations of people with dementia, their carers and mental health professionals. The questions were

- How do hallucinations affect the daily lives of people with dementia?
- Do hallucinations impact on the self identity of people with dementia?
- How do the multiple practices of dementia and hallucinations hang together?

My methodology used narrative triadic case studies with an ontological understanding of reality as enacted in situated practice. It allowed me to explore the multiple realities of my participants through their narrative realities. The narratives and their enactments were not fixed; they were continuously negotiated and renegotiated.

Using this methodology enabled me to elicit narratives of everyday life from people with dementia and their carers. It also allowed a space to explore how they jointly understood the impact of hallucinations on their lives. Clinical medicine relates to daily lives according to Mol (2008) and I would argue that this methodology demonstrated that clinical care by mental health nurses concerns daily lives.

Section 10.1.2 discussed the use of voice centred relational method in exploring the sense of self in participants. Although I have concentrated on the 2nd reading in this section the method also enabled an investigation of the way the ‘narrated subject’ (Doucet and Mauthner, 2008) is embedded in a social and interpersonal space. I would therefore argue that this method was suitable to answer the research question about identity.

My ontological understanding of multiplicity was reflected in the third question. Attending to narratives, especially of community mental health nurses showed how they moved fluidly between the understandings of categories or paradigmatic knowledge and the understandings of the particular. The nurses utilised different

knowledges, for example, when they assess that hallucinations appeared suddenly, it was likely to be caused by a delirium requiring treatment for an infection. Despite incongruities that can appear within a care setting the tensions were held together and there was ‘coherence without consistency’ (Law et al 2013). Care cut across the tensions (Moreira, 2010) and the most important response for them was to find the least bad responses for example not interfering when someone was not distressed by hallucinations, but this approach involved ‘tinkering’ (Mol et al., 2010), as it was flexible.

To summarise, the methodology I used in this study contributes to knowledge by proving a different understanding of hallucinations in dementia. It enables different ontological positioning to that of the dominant discourse by facilitating an examination of the individual experience. The use of I-poems in particular enables a method of ‘standing alongside’ rather than detachment from the research subject (Edwards and Weller, 2012). This contrasts with, and provides a different perspective to, that of medical diagnosis, which does not provide a meaningful reality for the individual (Bracken and Thomas, 2005). In the next three sections I go on to explore the theoretical contributions of the research in relation to a new understanding of hallucinations and dementia in liminality, relationships and multiplicity.

10.2 Liminality

One of the key findings of this study has been the ambiguous and shifting way in which hallucinations were understood by all three members of my triads, as discussed in the previous chapter on liminality. This stands in stark contrast to the way they are understood in the medical discourse, which firmly divides hallucinations from reality. In this study it is not the loss of reality that dominates the narratives but the desire to integrate the hallucinations into the narratives of biographical identity. Liminality explains the transgression of boundaries that was prevalent in this study. Borders between reality, dreaming, imagination, ‘true hallucinations’, misperceptions and past memories are crossed seemingly fluidly in hallucinations and dementia.

Hallucinations are ephemeral and elusive and to try to pin them down is a fruitless task; it changes their shape. Language is inadequate to try to describe them. They are at the same time meaningful and bizarre. Edith Turner describes the difficulties of understanding spirituality in its many guises

I know it is useless to try classifying and categorizing and clearing up the ambiguities in all of these, because each is right in its own context. Each shades into each.

(Turner, 2005: 259)

Her work on spirituality is intrinsically bound up with her husband Victor's work on liminality; they challenge the reductionism of dualisms, allowing an easy fluidity.

In this study I have used liminality as a concept for understanding the structural positioning of people who hallucinate and have dementia, and the experiential impact on individuals. The experiences of hallucinations and dementia were intrinsically linked, they were impossible to separate, and this complicates them both. Liminality provides a means of understanding hallucinations in dementia in a way that has not been met otherwise, either by the literature on hallucinations, or the literature on dementia. The living with dementia literature has not addressed living with hallucinations in dementia, despite it being viewed as indicative of a need for care (Leroi et al., 2003).

The concept of liminality was originally structural, a transitional state that is essentially unstructured (Turner, 1967). It can act as an explanation for the ambiguous understanding of the roles into which people are placed by society. People with dementia and people who have schizophrenia, where the predominant symptom may be hallucinations, are often placed by other people into an ambiguous category of not quite full members of society (Sabat et al., 2011, Barratt, 1998). This can also be conceptualised as the Self 3 of Sabat (2001), which is the role given by other people. In dementia, as has been argued in the consideration of the literature, people can be placed in an ambiguous situation by healthy ageing debates and epidemiological perspectives that position dementia as a social and political crisis, as well as the Enlightenment concept of the rational independent man. This thesis

provides an understanding of liminality that adds to the debate about how and why this ambiguity happens, the impact it may have on the individual, and the difficulty in changing this perspective. An individual in a liminal space is 'structurally invisible' to the rest of society (Turner, 1967). The analytic approach used in the study included a reading for how people place themselves within the broader social and cultural debates. It illustrated that my participants with dementia and their carers were aware of these debates about dementia, and were selective about revealing their diagnosis to others. Carers predominantly upheld the Self 3 of the people with dementia, although there was some ambiguity resulting from uncertainty and change in the person with dementia.

Kelly's (2008) study of living with AIDS dementia explored the psychological as well as the socio-cultural liminal spaces of the experiences of loss in AIDS dementia. This study too explores the internal emotional and psychological liminal spaces, but of hallucinations, rather than loss.

Liminality helps to understand the temporal slippages that may occur in dementia, and how hallucinations may incorporate aspects of the past into the present. The study demonstrates a multi-dimensional understanding of time and memory, challenging the predominant linear assumptions of narrative. Stories told about hallucinations are complex, they interrupt each other. Temporal sequencing of past, present and future interfere with each other. Carers attempt to smooth out time within relationships by assisting with linear constructions of narratives.

Most previous studies of liminality in health situations have explored some of the negative aspects of being in a liminal space, especially in the way that an ambiguous status results in loss of social visibility. Turner also describes liminality as an opportunity for reflection and freedom from institutional commitments. My participants with dementia were often playful in their approach to their hallucinations, viewing them not as negative but as creative.

My findings contrast with the definiteness of other understandings of hallucinations. Liminality presents a fluid understanding of hallucinations that are not problematic in

themselves. The experience of hallucinations may be both disabling and freeing rather than incapacitating. Liminality supports the vague, elusive and unknowable, allowing ambiguity, rather than othering them into the prescriptiveness of singularity because they are irrelevant or impossible.

10.3 Relationships

The medical understanding of hallucinations reflects the autonomous individual self of Western modernity. It assumes that hallucinations are the perceptual experiences of one person. The emotive and psychological effects of hallucinations were shared in relationships in this study. In contrast to the medical discourse of hallucinations, the data suggested that the meanings of hallucinations were constructed within relationships.

Recent research studies have seen a shift away from the dichotomised understanding of a split between the experiences of individuals with dementia and carer givers, to explorations of relationship focused understandings (Hydén and Nilsson, 2013, Hellström et al., 2005). In this study caregivers did not construct themselves as burdened, they structured relationships in complex ways, as couples or as daughter, father, but also as individuals. Relationships were not just reduced to caring relationships but working relationships, in line with other recent studies (Hydén and Nilsson, 2013, Taylor, 2008) An emotional closeness was apparent in all the interviews with people with dementia and carers demonstrated in their mutual use of humour, collaboration in telling stories and the use of 'we' in I-poems.

Nurses situated their understanding of hallucinations within a developing relationship with the person with dementia and their supporters. They demonstrated principles associated with an ethic of care, engaging with people in ways that demonstrated attentiveness, responsibility, competence and responsiveness. The findings of the study showed they gave more attention to the needs of people with dementia than carers, indicating that balancing differing needs can prove difficult.

Community mental health nurses positioned themselves as experts in the field of dementia and hallucinations, they were critical of others when they judged them

inattentive and incompetent. Nurses in care homes in particular came in for disapproval, being judged inattentive to the needs of people who were hallucinating, and incompetent in providing appropriate care. Responsibility requires spending time building up trust and a relationship (Barnes and Brannelly, 2008). The mental health nurses all identified this in their own practice, but they recognised that they were able to spend more time doing this, than care home staff.

The attentiveness of the nurses responded to the emotional needs of the person with dementia who hallucinated, rather than the imperative of the diagnosis. Tronto (1993) highlights that within responsiveness there is a recognition of a vulnerability in one of the parties. The mental health nurses' assessment of vulnerability was not based on whether the person with dementia was seeing things that deviated from consensual reality, but on whether it caused them distress.

The proliferation of recent interest in ethics of care have cautioned that providing complex care within systems with organisational demands is messy in practice (Barnes and Brannelly, 2008, Brannelly, 2011). Providing care for people with dementia and hallucinations is complex and needs skilled practitioners who are open to relational based care.

My findings contrast to the view that hallucinations in dementia inevitably precipitate an increased carer burden leading to requirement for institutionalisation (Leroi et al., 2003). Ethics of care challenges the view that those who need care are a burden and this study supports that challenge. An understanding of ethics of care also provides a more nuanced understanding of the care practised by mental health nurses and a framework to inform research relationships.

10.4 Multiplicity

None of the participants understood hallucinations using one dominant discourse; their understandings were multiple. The fluidity between categories was obvious in findings with everyone. In the analysis, it was apparent that hallucinations were not understood as reality disjunctures. A reality disjuncture implies that there is a

dichotomy between consensus reality and the reality of the person who hallucinates. Hallucinations were messy objects; they were viewed as fluid categories.

This did not mean that participants all had different perspectives of hallucinations, what was important to them was the reality of a particular situation. Coherence was not valued in understandings; practice involved situated knowledge rather than fixed categories. Participants had different understandings that they used in different situations, their knowledge was situated and they did not have difficulty in moving between knowledges.

Previous studies of hallucinations in dementia have mainly encompassed a medical understanding. This is the first study that has considered the understanding of community mental health nurses as far as I am aware. Cohen-Mansfield and Golander (2012) explored the perceptions of hallucinations by formal caregivers in an institutional setting but they were a mixture of trained and untrained staff. There were similarities in our findings of the difficulties for nurses in deciding whether an experience was a hallucination or not, but they attributed this to lack of training and discussion with residents, whereas I attribute it to the ambiguous and shifting nature of the experiences. Our findings also concur that hallucinations may be exacerbated where there is a lack of stimulation.

Although medical diagnosis is the role of the doctor, in practice nurses do become involved with this. Diagnosis may involve different realities and this was beautifully described by one of my participants in his description of suddenly being told he had hallucinations. Diagnosis is enacted out of the story of the patient and the embedded knowledge of the doctor and sometimes the nurse. When a person enters a room without a diagnosis, the diagnosis is enacted in a room, and requires two people. This does not mean that the person did not have something before, but had they something different; another reality. Stories do not always fit together.

Clinicians usually talk about a single object or sets of objects or processes that fit together. Hallucinations are no different; they are out there, anterior to and independent of medical intervention. When they discuss the specifics of one person

though, community mental health professionals enact differing realities rather than discovering or believing in one single reality. Their first task is to work out what reality is within a relationship, and the second task is to intervene and help. Sometimes it works smoothly, but at other times, realities are poorly coordinated. Medicine often works with multiple possible truths. What counts as the best, depends on circumstances, it may be best to try to work with the person to change the hallucination or it may be best not to do anything. Hallucinations can however change meaning for the person and so there is a need to attend to the fluidity.

10.5 Implications for practice

I am a nurse and my motivation for this study was to inform practice. The value of being with people in relationships is to hear narrative understandings. This enables practitioners to engage in an attentive way to enhance recognition of complexity and inform treatment decisions. The idea of person centred care (Kitwood, 1997) and the importance of nurse-patient relationships (Altschul, 1972, Peplau, 1988) are not new. Relational care has the potential to enhance personhood. As Kittay (2005) reminds us, personhood may be a contested term, but it has a real life urgency for those whose personhood is at stake.

Using an ethic of care understanding requires an attentiveness to need and also that the person receiving the care is responsive. If the person who experiences hallucinations is not distressed by them then it is questionable that there is a need. At the level of treatment delivery, the research findings point to the need to attend to the meaning of hallucinations for the person with dementia and their carer. If hallucinations are not currently producing a threat to that person then there is no necessity to attempt to intervene, especially with medication that has consequences for the person receiving it. There has been enough evidence that antipsychotic medication can produce serious adverse effects for older people with dementia (Ballard et al., 2009, Banerjee, 2009). Some people with dementia may wish to learn techniques to control their hallucinations, or to establish the veracity of differing realities. The study showed that practitioners in collaboration with people living

with dementia can help to develop strategies to assist with this in certain circumstances.

There were a number of occasions described in these interviews, where the use of the symptom ‘hallucinations’ was given to someone without considering its effects. In my study two people with dementia had found it amusing or interesting, turning the medical interview into an object of their view rather than vice versa, but the evidence on the social effects of giving such a diagnosis have been well enough documented to require professionals to think more carefully. Other instances include the use of the term by people who were ill qualified to do so, which had implications for the way in which people will be treated.

Although my understanding of hallucinations at the beginning of the project was that it was a slippery concept that could include misperceptions and illusions, I still located it as a mental health problem. It was a concept that could be shared with other mental health professionals as shorthand for a multiplicity of experiences. My opinion has now changed about its use. The term comes with too many negative connotations for society and can be meaningless for the individual who experiences them. It was understood by my participants as stimulation in the absence of other social stimuli, memories, imagination, creativity and dreams. I now believe that the most important response is one based on the emotional impact it has for the person experiencing it.

A medical definition of hallucinations is inadequate in dementia. Practitioners need to listen to the experiences of people and use descriptive accounts as given by the person with dementia, rather than ‘hallucinations’, which means little, either to a person with dementia, or often to a nurse. If dementia is a conceptual mess as Hughes (2011) argues, the term ‘hallucinations’ is equally so, and serves little purpose as opposed to dementia.

Woods (2013) argues that people who heard voices did not exist before 1987 when the Hearing Voices Movement developed a new way that people could talk about their experience. Perhaps there are people with dementia who have already started to

challenge the predominant discourses of dementia, who may also challenge the decontextualized discourse of the DSM (Diagnostic and Statistical Manual) (American Psychiatric Association, 2013). Mental health practitioners are well placed to support a development of that debate.

10.5.1 Recommendations

- The findings from this study highlight the importance of relationships within care. Nurses in all areas, including care homes, need to spend time with people with dementia who hallucinate, listening to their narratives.
- Seeing things that others do not, is not necessarily a negative experience for someone with dementia. Assessment for well-being should be based on the meaning of the experiences for the person with dementia rather than their divergence from consensus reality.
- The term ‘hallucinations’ does not reflect the lived experience of people with dementia, their carers, nor the understandings of the different realities seen by nurses. There is a value attached to it that can disadvantage those receiving it. Practitioners need to address its usefulness and consider using other terminology that is more descriptive of the person’s understanding. This would be person specific but may include terms such as vivid dreams or seeing things that other people do not.

10.6 Limitations of the study

As I was critical of other studies that collected data about the experiences of people with dementia from formal and family caregivers, I cannot ignore the limitations of my study.

My initial understanding of hallucinations situated them within a community mental health context. This meant that the pool of potential recruits was small and may have been biased towards those perceived as having a behavioural problem and in need of mental health services.

The findings may have been strengthened if my sample had been larger and more diverse. I had hoped to recruit a sample of five people with dementia but difficulty

in recruiting meant I only managed to recruit three. Although two more participants may not have made much difference it may have provided more diversity. The thick data that can be produced from a case study, however, allows an exploration of complexity (Flyvbjerg, 2006).

My criteria excluded people who would become distressed talking about hallucinations. The voices of people who are disturbed by hallucinations were reported through accounts of professionals. They describe distress as a predominant cause for concern within their practice. This means that the findings may not be representative of the referrals to the mental health services.

The voices of women who hallucinate, and male carers, are also absent. Gilligan (1982) identified gender differences in the development of moral reasoning, and there are gendered assumptions of care (Tronto, 1993, Barnes, 2012) and so this study is unbalanced. Despite these limitations, the study is a beginning in exploring narrative understandings of hallucinations in dementia.

The interviews with carers differed due to the preferences of the people with dementia and the carers. One of the participants with dementia wanted his wife to be present through all the interviews, the other two carers were only interviewed once. Both chose to be interviewed with the person they looked after present but it would be a mistake to see these as much of an examination of their relationship. They were not asked to focus on something that predominantly affects them as a social unit but their individual understandings. They were asked about the experiences of hallucinations of the other person, rather than having an interactive focus. The analysis highlighted some interactional aspects of their relationships, but the task differed from that in studies such as Hydén and Nilsson (2013).

Neither the aim of the study, nor the methodology used, was intended to produce data that was representative of the whole population of people living with dementia and hallucinations. It is situated and partial knowledge, contingent rather than objective, its value is in sensitizing the reader to issues that arose in the narratives of

these participants. Despite this I hope the narratives would be recognisable to other mental health nurses.

10.7 Future research

The current study has challenged the medical discourse of hallucinations by demonstrating that people with dementia and carers integrate them into their narrative identity. Further studies should be undertaken with wider and more diverse samples to examine the impact of different variables such as gender or ethnicity on how hallucinations are understood by people with dementia, carers and other professionals.

Further research could engage with how to enhance more helpful responses to hallucinations, especially in different care environments. Whilst not underestimating the challenges for care homes in terms of workloads and staff turnover, responses to hallucinations that are inappropriate can cause further distress to people with dementia and possibly escalate distress. Supporting meaning making by attending to narratives of both people with dementia and carers who have a shared narrative history will enhance well being

The dissonance between the experiences of all participants and medical diagnostic processes could be explored. Wider studies of mental health professionals may increase pressure to abandon the use of the terminology of hallucinations.

There are increased research and policy imperatives to be more inclusive in considering the experience of people with dementia and carers. The research methods used in this study facilitated listening to narratives, and could be applied in other studies in dementia, and other areas where care is provided.

10.8 Final reflections

The thesis is situated knowledge and therefore I do not make definitive claims. It makes a contribution to on-going research, but does not provide a conclusion. My initial expectations that I would achieve one understanding or theory of hallucinations in dementia, and change practice now seem unrealistic and naïve.

The understandings developed during this study have helped me to realise that there is no meta-narrative to be found. I have become comfortable making sense of experiences and relationships within contexts. This study has underlined the complexity of both hallucinations and responses in dementia; in many ways they are unspeakable and unknowable, they are fleeting and ephemeral and liminal.

I have questioned my understandings of reality and hallucinations, and found them inadequate. If I let go of my belief in a single, independent, anterior and definite reality, hallucinations can be accepted as ambiguous and fragmentary. I have also had to confront my conflict about the preservation of self in dementia, and what this means for people with dementia and for relatives. This involved examining my experiences as a daughter to unpick some of the ambiguities involved within emotional relationships.

My interrogation of my own practices has been through reflexivity. I hope I have avoided the pitfall articulated by Jane Speedy (2013) of using reflexivity to discuss my unmessy, sorted thinking in contrast to my participants' messy stories. I would like with her to claim some solidarity with the unsorted and unsafe. I have come full circle from confidence in my professional knowledge, through uncertainty about any certainty, to a reasonable comfort with the uncertainty of the metanarratives, and a certainty that we need to attend to the specifics. There are different knowledge claims used in mental health nursing and these can be accommodated in situated knowledge, in partiality but not in universality (Haraway, 1988).

Returning to the story of Alex in Chapter 1, this study has not explained to me what was happening for Alex, but it has helped to explain why my final response may have worked. Somehow I recognised that his need for care was about feeling secure, I was able to act and he received what I said to him, as care. This use of ethics of care (Tronto, 1993) sounds deceptively simple, at that moment we were therapeutically connected but as the data from other nurses show it is complex and multiple.

One of my regrets in concluding this thesis is that I have been unable adequately to capture the dynamic nature of my research encounters. The examination of one aspect of a person's life will always be a sleight of hand, and although hallucinations and dementia are the aspects of their identity that are inevitably portrayed here, they say little of the participants' humour and ability to maintain warm relationships. Graeme's hall may be the site of hallucinations but with its photographs and degree certificates, it is also a reminder of his achievements throughout his life.

11 References

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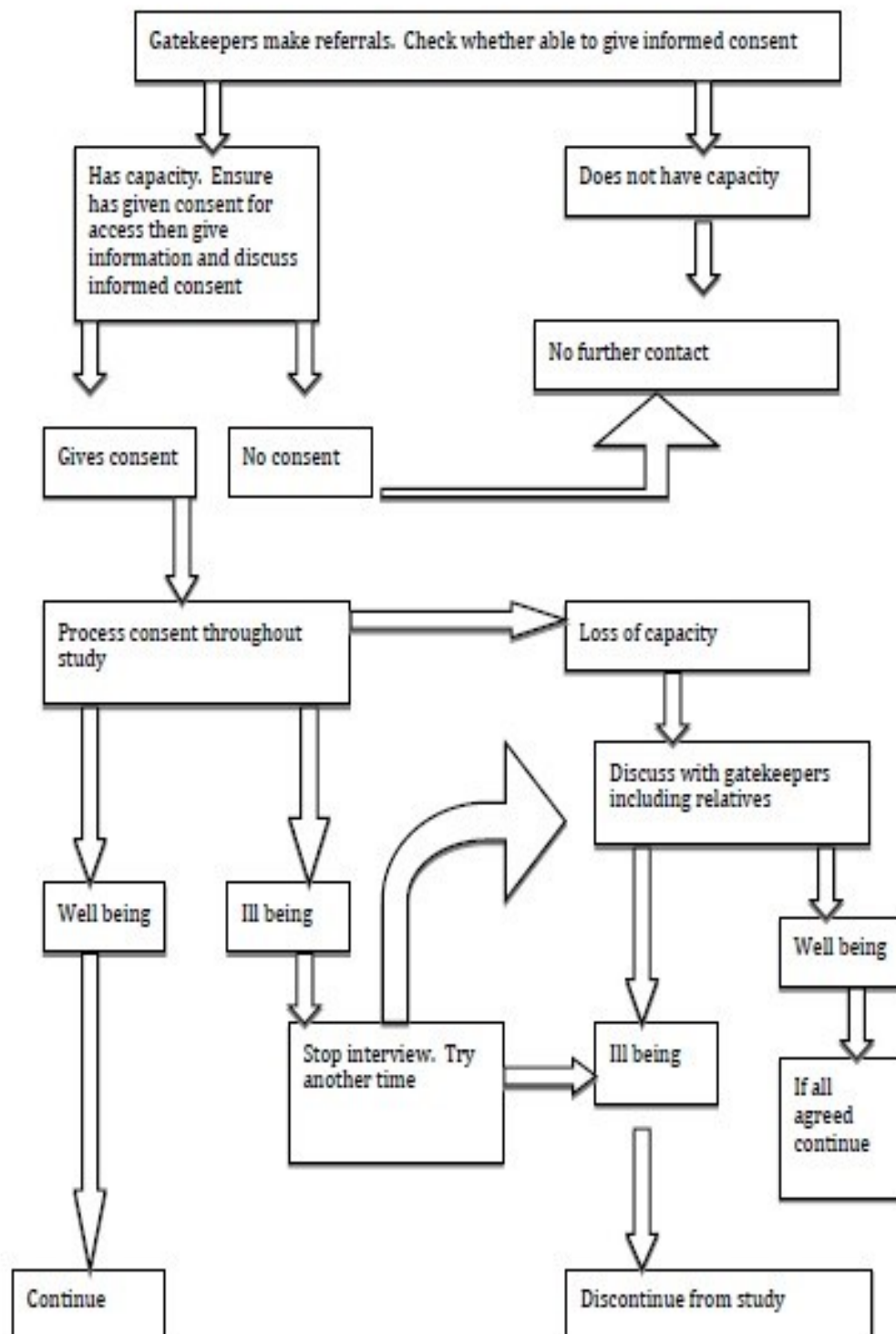
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Consent Process



APPENDIX 2:

INFORMATION SHEET FOR PEOPLE WITH DEMENTIA AND FAMILIES



About Liz

I am studying at the University of Edinburgh. I am trying to find out what it is like for people who have problems with their memory and sometimes experience things differently to other people. This may sometimes be called hallucinations.

I want to understand how this affects everyday life and relationships and how people cope with this.

My aim is to use this information to help other people including nurses to find the best ways of supporting people like you.

What if I've got questions?

If you want to ask anything about the work please get in touch with

Liz Taylor

Tel: 07765094760

School of Health in Social Science,
University of Edinburgh, Teviot
Place, Edinburgh, EH8 9AG
B.E.Taylor@sms.ed.ac.uk

What if I have concerns?

If you have concerns that you would like to discuss with someone independent of the study, please get in touch with

Dr Marion Smith,

Postgraduate research coordinator

Tel: 0131 651 3966

School of Health in Social Science,
University of Edinburgh, Teviot
Place, Edinburgh EH8 9AG

Marion.smith@ed.ac.uk

Differing realities in dementia

A research project



Liz Taylor

School of Health in Social
Science

University of Edinburgh

Information for people with
memory problems and families

Taking part in the research

What will it involve?

I would like to speak to people who have memory problems and people they are close to.

If you agree to take part, I will want to spend some time getting to know you and the person closest to you such as a family member or friend. This will involve visiting you both in your home and asking what it is like for you having memory problems and sometimes seeing different things from other people around you. I will want to come and see you around five times in all over a 6 – 9 month period.

You can choose to say no to this study and your decision will be respected. It will not affect the

care you get from the community staff. If you agree to take part, you can change your mind at any time or if there are things you would rather not talk about that is fine. If you agree to take part I will let your community nurse know.

I will want to record some of our conversations and I may want to quote what you say. If I do I will make sure that neither you nor your family can be identified

If you think you might want to be involved please let your community nurse or me know. I will then arrange to come and visit you to talk about the project and answer any questions you may have.

What will happen as a result of the work?

I will write a thesis for the University of Edinburgh. I will also write some articles that will be read by other researchers and people who work with people like you.

In the end I hope that the work will help health workers and others to know how to support you better.

What happens next?

I would like to know if you want to take part. You might want to spend some time talking to your relative or community nurse about this.

APPENDIX 3:

INFORMATION SHEET FOR
PROFESSIONALS



About Me

I am currently studying for a PhD at the University of Edinburgh. I would like to understand more about the experiences of people who have dementia and hallucinations. I want to explore how experiencing things differently affects the daily life and relationships of people with dementia and their carers and how they deal with this.

I also want to take into account the perspectives of mental health team members. My aim is to use this information to contribute to the development of the best ways of supporting people.

What if I've got questions?

If you want to ask anything about the work please get in touch with

Liz Taylor

Tel: 07765094760

School of Health in Social Science,
University of Edinburgh, Teviot
Place, Edinburgh, EH8 9AG
B.E.Taylor@sms.ed.ac.uk

What if I have concerns?

If you have concerns that you would like to discuss with someone independent of the study, please get in touch with

Dr Marion Smith,

Postgraduate research coordinator

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University of Edinburgh, Teviot
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Marion.smith@ed.ac.uk

Differing realities in dementia

A research project



Liz Taylor

School of Health in Social
Science

University of Edinburgh

Information for mental
health professionals

What will it involve?

I would like to interview people who have dementia and hallucinations and their carer in order to understand their experiences. This will involve visiting them at home and asking what it is like having memory problems and sometimes seeing different things from other people.

It will involve around 5 visits, and speaking to people with dementia and carers. The people with dementia need to have capacity to agree to the study and both people with dementia and carers need to be willing to participate.

If there is any change in capacity during the study I will discuss with you and the carer whether they should continue in the study. If the person with dementia becomes upset at any time the interview will be discontinued.

I would also like to talk to professionals (nurses and OTs) about their experiences and

perspectives of hallucinations. This would involve taking part in one discussion group with other professionals, lasting around 1-1½ hours. You will be asked about your experiences of people with dementia who hallucinate and how you have supported them.

I will want to record the discussion group and some of the interviews with people with dementia and carers. Anything said will remain confidential. The recording will only be available to myself and supervisors. If direct quotes are used they will be anonymised and you, the person with dementia and their families will not be identifiable

What happens next?

If you can think of any people with dementia and their carers who may be interested in this project, I

would like you to ask them if they would be willing to discuss this with me. I will arrange to visit them to talk about what would be involved.

If you would be interested in taking part in a group session with other professionals to discuss your experience could you let me know?

What will happen as a result of the work?

Once I have gathered information and experience from people, I will write a doctoral thesis for the University of Edinburgh. I hope that the findings will be helpful for professionals in informing practice.

A summary report will be written and made available to your team and I will be happy to return to discuss my findings.

APPENDIX 4: Consent form person with dementia

**Differing realities in dementia
Consent Form
People with memory problems**



I have spoken to Liz Taylor about the study

This meeting took place on(date)

	Tick One Box	
	Yes	No
I have had a chance to look at the information sheet and ask questions	<input type="checkbox"/>	<input type="checkbox"/>
I know enough about the work now to make a decision on taking part	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I can chose to take part or not	<input type="checkbox"/>	<input type="checkbox"/>
I understand that if I don't want to take part I don't have to give a reason	<input type="checkbox"/>	<input type="checkbox"/>
I understand that if I do take part our interviews will be recorded	<input type="checkbox"/>	<input type="checkbox"/>
I understand that if I do take part, I can withdraw at any time without giving a reason	<input type="checkbox"/>	<input type="checkbox"/>
I understand that if I do not want to take part this will not affect any service I get now or in the future	<input type="checkbox"/>	<input type="checkbox"/>
I agree to take part in the study	<input type="checkbox"/>	<input type="checkbox"/>

Signed.....Date.....

Name (in block letters).....

Researcher.....Date.....

APPENDIX 5: Consent form carer

**Differing realities in dementia
Consent Form
Relatives & friends**



I have spoken to Liz Taylor about the study

This meeting took place on(date)

	Tick One Box	
	Yes	No
I have had a chance to look at the information sheet and ask questions	<input type="checkbox"/>	<input type="checkbox"/>
I know enough about the work now to make a decision on taking part	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I can chose to take part or not	<input type="checkbox"/>	<input type="checkbox"/>
I understand that if I don't want to take part I don't have to give a reason	<input type="checkbox"/>	<input type="checkbox"/>
I understand that if I do take part our interviews will be recorded	<input type="checkbox"/>	<input type="checkbox"/>
I understand that if I do take part, I can withdraw at any time without giving a reason	<input type="checkbox"/>	<input type="checkbox"/>
I understand that if I do not want to take part this will not affect any service my relative and I get now or in the future	<input type="checkbox"/>	<input type="checkbox"/>
I agree to take part in the study	<input type="checkbox"/>	<input type="checkbox"/>

Signed.....Date.....

Name (in block letters).....

Researcher.....Date.....

APPENDIX 6: Consent form professional

**Differing realities in dementia
Consent Form
Mental health professionals**



I have spoken to Liz Taylor about the study

This meeting took place on(date)

	Tick One Box	
	Yes	No
I have looked at the information sheet	<input type="checkbox"/>	<input type="checkbox"/>
I have had a chance to ask questions	<input type="checkbox"/>	<input type="checkbox"/>
I know enough about the work now to make a decision on taking part	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I can chose to take part or not	<input type="checkbox"/>	<input type="checkbox"/>
I understand that if I don't want to take part I don't have to give a reason	<input type="checkbox"/>	<input type="checkbox"/>
I understand that if I do take part, the interview will be recorded	<input type="checkbox"/>	<input type="checkbox"/>
I understand that if I do take part, I can withdraw at any time without giving a reason	<input type="checkbox"/>	<input type="checkbox"/>
I agree to take part in the study	<input type="checkbox"/>	<input type="checkbox"/>

Signed.....Date.....

Name (in block letters).....

Researcher.....Date.....

APPENDIX 7: Listener's guide

THE LISTENER'S GUIDE (Brown and Gilligan, 1992) (Mauthner and Doucet)

TEMPLATE FOR ANALYSIS (Emma Carduff)

1 a) OVERALL PLOT

- i) Listen to the overall story to get a sense of what is happening and the events which unfold over the course of the transcript
- ii) Note the who, what, when, where and why of the narrative
- iii) Questions to post of the narrative:
 - Are there recurring words?
 - Are there recurring images?
 - Is there a central metaphor?
 - What are the emotional resonances?
 - Are there contradictions within the narrative?
 - Are there inconsistencies in style?
 - Are there revisions and/or absences in the story?

1 b) READER RESPONSE

We have to reflect on ourselves as people in the privileged position of interpreting the life events of another and consider the implications of this act

- i) Questions to aid reflection:
 - In what ways do we identify with or distance ourselves from this person?
 - In what ways are our experiences different or the same?
 - Where are we confused or puzzled?
 - Where are we certain?
 - Are we upset or delighted by the story, amused or pleased, disturbed or angered?

2) THE VOICE OF 'I'

Allows the researched to focus on the active voice of I which is telling the story

- How does the respondent experience, feel and speak about her/himself?
- Are there changes in the use of I, we which signals changes in how the respondent perceives and experiences her/himself?

3) READING FOR RELATIONSHIPS

How does he/she experience him/herself in the relational landscapes of human life?

Relationship with family, friends, health service, GP, relationship with self and body, time, the wider patient collective, other people with dementia, God or other higher being

APPENDIX 7: Listener's guide

4) SOCIAL, CULTURAL AND POLITICAL CONTEXTS

In what societal and cultural frameworks is this voice being heard and story being told?

What are the cultural contexts?

Cultural norms and expectations:

Social structures?

Health care structures – expectations of health service

Gender, class, age, sexuality

Home structures

APPENDIX 8: Listener's guide

JOINT INTERVIEW

THE LISTENER'S GUIDE (Brown and Gilligan, 1992) (Mauthner and Doucet)

TEMPLATE FOR ANALYSIS (Emma Carduff)

1 a) OVERALL PLOT

- i) Listen to the overall story to get a sense of what is happening and the events which unfold over the course of the transcript

Participant story:

Carer story:

- ii) Note the who, what, when, where and why of the narrative
- iii) Questions to post of the narrative:
 - Are there recurring words?
 - Are there recurring images?
 - Is there a central metaphor?
 - What are the emotional resonances?
 - Are there contradictions within the narrative?
 - Are there inconsistencies in style?
 - Are there revisions and/or absences in the story?

1 b) READER RESPONSE

We have to reflect on ourselves as people in the privileged position of interpreting the life events of another and consider the implications of this act

- i) Questions to aid reflection:
 - In what ways do we identify with or distance ourselves from this person?
 - In what ways are our experiences different or the same?
 - Where are we confused or puzzled?
 - Where are we certain?
 - Are we upset or delighted by the story, amused or pleased, disturbed or angered?

2) THE VOICE OF 'I'

Allows the researched to focus on the active voice of I which is telling the story

- How does the respondent experience, feel and speak about her/himself?
- How does the carer speak about her/himself?
- How do they speak about each other?

APPENDIX 8: Listener's guide

- Are there changes in the use of I, we which signals changes in how the respondent perceives and experiences her/himself?

3) READING FOR RELATIONSHIPS

How he/she views him/herself in the relational landscapes of human life

Relationship with family, friends, health service, GP, relationship with self and body, time, the wider patient collective, other people with dementia, God or other higher being

- Carer/person with dementia relationship

4) SOCIAL, CULTURAL AND POLITICAL CONTEXTS

In what societal and cultural frameworks is this voice being heard and story being told?

What are the cultural contexts?

Cultural norms and expectations:

Social structures?

Health care structures – expectations of health service

Gender, class, age, sexuality

Home structures

APPENDIX 9:

WORD CLOUD

Dave Word cloud-joint interview



APPENDIX 10:

DATA INTERPRETATION PROCESS

